

RAISING OLIVER

Advocacy of a special need 1982-2012

PHILLIP MEDHURST

Cover: "Sunrise" by Oliver Medhurst, painted by mouth

PART 1: THE AFTERMATH. 1982-1985

Journal. 26 September 1982 [Sunday] It will be six weeks on Tuesday since Oliver was run down by a car on the dual carriageway at the bottom of our street. He now appears to be growing stronger, and in purely physical terms the worst seems to be over. But there is much about Oliver's present state that is difficult to interpret, and this is one reason why I have decided to make notes on his progress. The other reasons, I am sure, will become apparent as this journal progresses.

The exact circumstances of my son's accident have not been ascertained and probably never will be. Among the plethora of fickle testimonies painstakingly compiled by the police, and which, in view of their superfluity in legal terms I have declined to read, my wife and I have alighted on one. My wife could probably recount the details of which shopkeeper or eagle-eyed neighbour originally communicated this narrative, but whether observation or surmise, it is the version which rings true to me.

According to this, Oliver, no doubt in his habitual state of athletic excitability and boyish urgency, was at the pelican crossing having fulfilled his errand of buying a cake. It being summer holiday time, Jackie, myself, grandpa and Oliver had just shared a fish and chip lunch at my father's house. Having improvised the first course, we agreed to improvise the second, and sent Oliver on his five minute journey to the local shops. My last memory of him before the catastrophe sees him seated at the dining-table, his peaked cap [a present from Holland] pulled determinedly over his temples, methodically devouring the rough-and-ready delicacy. He was clearly pleased to be part of this intimate and exclusively adult family circle [his sister being elsewhere], gleefully tolerating the turgidity of adult conversation in exchange for inclusion as we discussed the logistics of conveying Oliver's sister to and from her new school.

What happened to him after he received his instructions and departed on his errand [a chore so mundane that I hardly noticed his absence in my absorption with the daily paper] is partly a matter of speculation. It seems that, while waiting impatiently at the crossing, mission accomplished, a lady took her chance, ignored the signals, and crossed. Oliver followed her example. He was struck by a car. He broke both legs and sustained a serious head injury. A shopkeeper called an ambulance.

Meanwhile, my wife, concerned as to his whereabouts, had made a brief foray. Seeing the maelstrom of flashing lights, signalling uniforms and static pedestrians it registered instantly as the mother's nightmare.

Still absorbed in tabloid trivia like a sunbather on the edge of a crumbling precipice, I had no idea that the ring of the doorbell which drew me so unwillingly from my complacent lethargy was a summons to Hell. The child, Oliver's friend, said simply, "Oliver's been run over."

I wanted to cry out. Instead, I ran. I did not run at my fastest because that was to admit something unthinkable. The traffic had stopped on the opposite carriageway. I reached the crossing. Someone said "Here's his father." Ironically, I remember methodically pressing the signal button on the crossing and waiting patiently for the traffic to stop. An official of indeterminate uniform stepped forward to halt it. I crossed. Jackie stood weeping. Oliver was in the ambulance. We got in. Then followed the tumble into the abyss: the ambulance rocking and lurching as though tossed on the sea of Chaos; the gruesome rattle of the suction-tube; the intense glances and cryptic murmurs of the ambulance-men; the studied abandon of the driver. Oliver kicking, turning his head, rolling his eyes. The smudge and smear of blood. The paleness and trembling and uncomprehending stare of his mother. The clenching jaw Arriving at the Infirmary.

Journal. 3 October 1982 [Sunday] Oliver was in intensive care for two weeks following an operation to deal with internal bleeding in the skull. The problem was to control pressure on the brain due to swelling. Treatment included heavy sedation and the use of a ventilator inserted via tracheotomy. After I.T.U. and successful control and reduction of pressure Oliver was passed on to a children's ward. Last week-end [ie. nearly one month after I.T.U.] he seemed to be on the road to improvement. While not "conscious" in the normal sense he was breathing for himself, he could move his hands, arms, head, toes, eyes and make sounds. He reacted to sound. This was encouraging even if he did not respond to verbal instructions. There seemed to be no paralysis apart from his right pupil which did not [and still does not] react to light. He was not "seeing" and "hearing" [as far as we can understand] in the normal sense, but the fact that he "jumped" at a sudden

clatter encouraged us to play tapes. His increasing strength encouraged us to sit him up in bed [as far as the leg-plasters allowed] using our own bodies as support. While seated on the bed in this way it was difficult to see reaction since we were facing the same way, but observing Jackie in this posture with him last Sunday it seemed that he was reacting to affection. His arms were relaxed, as were the muscles round his mouth. When Jackie kissed him on the lips he opened his mouth as if for more; when I kissed him he curled his upper lip, clearly preferring his mother's scented embrace to my grizzled overtures. Things seemed to be moving.

Then, last Sunday night, we received a call from the hospital: Oliver was having breathing difficulties; he seemed to have an obstruction in his throat. The demon of anguished shock woke up with a vengeance; the ride to the hospital was like a nightmare recall of the ambulance terror. It was probably a fit. We had not anticipated setbacks. When the crisis passed, we were all left very low. But that dreary train of events is still being lived through, and its telling demands more energy than I have now

Journal. 4 October 1982 [Monday] Now, as I write, Oliver is undergoing an operation. I have already mentioned the setback of last week. On that difficult night a nurse called Fiona, who seems to have a special affection for Oliver, noticed that he was experiencing breathing difficulties. The nearest doctor to hand, an anaesthetist, was called into the ward. She knew nothing of him. He was given oxygen orally, his tracheotomy-pipe having been removed just over a week before. Just after we arrived Dr. O'C. came in, one of the doctors from I.T.U. He inserted an airway in his mouth. This has remained since that time. He speculated, since there was no obstruction and his chest was clear, that Oliver was having a fit, and prescribed an anti-epilepsy drug.

Gradually, the crisis subsided. I arranged for Jackie to be taken home and I stayed at the hospital that night. Eventually Oliver passed into a deep and tranquil sleep. Before this, however, I saw the tense spasmodic movement of the arms which, according to the night staff, had not been uncommon at night. It showed an aspect of Oliver's state which I had been completely unaware of. It seemed to open a trapdoor into the darkness of another storey of his damaged mind.

Throughout the following week he seemed very tired and his general level of awareness appeared to be in decline. The paediatrician, Dr. M., seemed puzzled and worried: Oliver's blood-pressure was high and was having to be controlled by drugs. Clearly, something was wrong inside Oliver's head, although we were pleased by his efforts to remove the nasal airway which had been inserted later on the difficult night, and the nasal-gastric tube by means of which he was being fed. This indicated, I believe, Oliver's basic problem. Under the impact of the hurt and shock, Oliver's mind [if I may use a word whose meaning I am not sure of] had retreated into some dark, closed void. Each new "therapeutic" procedure, aimed at relieving his physical state, seemed a jarring re-iteration of that first psychic shattering. Skull incisions, suction, alien murmurs, arm incisions, throat insertions, encased legs anaesthetic bludgeons, the throb of swelling and cuts and sores and knitting, and the pain of the hurt that had forced its way deep inside his body's citadel and crashed into the watchtower of his being, all were the reiterated roars, jabs, and twists of the demon that was upon him. Cradled in his mother's arm that Sunday the demon was, perhaps, slumbering, and Oliver was stirring as if to creep to the mouth of the lair, into the light and warmth which we longed to share with him. But something happened that night to drive him back to huddle in a corner of the cave. Maybe a fit, another callous blow from the demon's brutish arm, a warning cuff to stifle the lure of sunshine. Or perhaps Oliver's nerve failed him. Dr. M. does not seem to believe it was a fit, and appeared irritated by Dr. O. C.'s prescription of a perhaps top-heavy dose of the epilepsy drug. The demon if stunned, had pinned down his thrall beneath his dominant mass. No. Dr. M. thought that, venturing out, Oliver had turned to the support of his breathing tube, to find it gone. It was a momentary panic of the emerging psyche. Is it just a father's fancy to recall the breathless panic that I too have been experiencing these nights in the face of a deep and comfortless sleep, and to believe that this is just a shadow of the darkness that now envelopes my son, whose soul is linked to mine by silken threads that still twitch at the labyrinth's mouth?

I know and love Oliver. This enigma, this unresolved wonder of our familial love, deep down beyond the mere accidents of intelligence and perception, is: I know him. We will not part. Nothing, not even death, can divide us. My soul hurls a challenge to Chaos. Evil must vent its fury and spend itself; it knows it cannot win.

Throughout this time some continuing consultation had been going on with neurologists at Derby Royal Infirmary. Oliver was not getting better and something had to be done. No doubt on the evidence of the scans [no-one seemed to make much sense of an E.E.G.] Derby diagnosed a build-up of fluid. This could be relieved by inserting a tube internally to drain the fluid into some comparable cavity in his abdomen; my knowledge of anatomy is vague. This wondrous device may relieve his condition and lead to progress, or it might not. We shall see. I am not over-optimistic. While not ungrateful for the surgical techniques which have indeed saved Oliver's life and prevented God knows what suffering, I believe that the Problem is far more deep and complex than the surgeon's knife can solve, and it is not just Oliver's problem. It is a moral problem: coping with handicap. It is an emotional problem: channelling feeling into healing and creativity. It is an intellectual problem: how does the brain actually work? It is a problem of the re-ordering of priorities, the re-orientation of values: not just of the little world of Jackie and myself, but of the whole world, yes, even the cosmos. I dare to say that my own little family problem is indeed earth-shattering or the dawn of a new age in that spiritual sphere where human scale is unimportant. We shall see

Despite further violent, if benign, assaults on Oliver's physical integrity [an operation labelled with endearing simplicity as "the shunt"], surgery seems to have had an almost instant effect. Sitting here beside his bed, I see that his eyes are very slightly open with rapid to-and-fro movements. His hands are relaxed and his arms [particularly his left] are moving gently, although contracted at the elbow. His left leg moves spontaneously at intervals; earlier this afternoon he was moaning insistently. He now looks more bewildered than withdrawn. I guess that there is now some ground for cautious optimism.

Journal. 27 October 1982 [Wednesday] On arrival [about 5.00 p.m.] I propped up Oliver against my chest with my left hand flattened against my chest. For about four minutes he emitted a series of moans including one load moan, almost a cry. [My father had clearly heard the same sound. Last Friday he claims that he shouted "Oi" when father was moving his head from side to side. On the same day nurses claim that he "shouted" when taken out of the bath.] Conclusion: this may be in

response to unusual, though not necessarily unpleasant, sensations. It probably indicates and articulates objection, and may be a positive progression from the movements we witnessed before the ventricular-peritoneal shunt was inserted: bringing his hands to his face in a "cringing"-type action. I believe it indicates a very basic attempt to relate to his environment through elementary communication.

We had not experienced any evidence of will or effort since his attempts at Derby to nudge out his naso-gastric tube. These attempts have since subsided, possibly because his nose is no longer sore after a clumsy insertion of an E.T. tube during his "fit". Today I tried shaking his left hand loosely at the wrist. After about six seconds on three consecutive tests he pulled his hand away. It was a weak action, but unmistakable. I fail to see how this can be interpreted simply as "reflex".

Journal. 3 November 1982 [Wednesday] Having read a little about ontogeny, it appears that Oliver currently has the responses of a one-month-old baby. It is still open to question whether or not we could move him on towards the responses of a three-month-old child. It is unclear at this stage whether the handicaps are neurological or psychological. My body is yours; my brain is yours; your soul is entrusted to me.

If Oliver's "problem" is psychological, then we must provide him with the comforts of the womb, while coaxing him towards birth. This is the prime aim of his mother. If his "problem" is neurological, then we must extend his brain, both as receptor and emitter, by means of electronics. This is the prime aim of his father.

Journal. 2 December 1982 [Thursday] Oliver has made some small but encouraging progress over the last couple of weeks, the most rewarding of which is his new-found ability to smile. Although this does little to overcome his physical problems, it is a tremendous boost to morale. When it first happened [I was talking to him about his favourite foods] Jackie and I were together. This was great. If either of us had reported the "event" to the other, it would have been met with incredulity. As it was, it happened three times "on the trot": chocolate . . . smile and "coo"; ice cream . . . smile and "coo"; cake . . . smile and "coo". And yesterday, for the first time, he smiled at what he heard on tape [no doubt recognising John Pertwee as "Wurzel Gummidge"]. This is personality.

Much more important in medical terms is his growing ability to swallow. He began to take baby-food about three weeks ago, and now has two liquidised meals a day. Consequently, he is now physically a great deal more robust. The physiotherapists continue to spend a great deal of time with him, and have just started to take him out of the ward. They seem rather clandestine in their behaviour. Whether this is because they are jealous of their "trade secrets", or because they are trying something along the lines of "patterning" - establishing the correlative mental circuits appropriate to his next stage of development. At the moment it's difficult to establish a dialogue with the physio's: they operate in the early afternoon when I don't normally visit. But since everyone is now talking about a training or induction week for Jackie and myself at the hospital after Christmas [an introduction to some of the problems we might meet in nursing Oliver at home], I guess there will be more fruitful contact with the physiotherapists then. I see them as the hospital's major input at the moment. Oliver is now not simply "not stiff": he is supple. It's good to see him tired in the evening. It must be a great aid to real healing sleep and a creative antidote to boredom and frustration.

We hope that we are on the threshold of some communication with Oliver. It seems [Jackie is more convinced than I am] that he will both blink and widen his eyes to instruction. Experimenting yesterday, he did seem to be doing this. The telling point is that when congratulated on his clear response to instructions, he smiled. This could be a major breakthrough. As far as we can see, he has no comparable control over any other part of his body, although there is a shade of co-operative movement in his arms. Dare we begin to think of a system of codes? Our biggest worry now is our future domestic arrangements. I hope the picture will become clearer in the next few days

Letter. 15 December 1982. To: Head of Special Education Section, County Hall, Leicester. [Mr. L.]

I am writing to you in connection with my son who is nominally a pupil at Belgrave C. of E. Primary School, Leicester.

Oliver sustained a serious head injury resulting in brain damage as a result of a road traffic accident last August. He is now undergoing treatment in Children's Ward 11 at the Leicester Royal Infirmary under the supervision of Dr. M. Domestic problems are being dealt with by Miss C. P., the Hospital Social Worker.

The competence and commitment of Mrs. V. P. [acting Headmistress] and her staff at the L.R.I. School are above question. Nevertheless, Oliver undoubtedly has special educational needs which they are not necessarily trained to meet. I would be very glad to initiate some discussion and consultation regarding any special provision which can or should be made for him both in the short- and long term.

Without wishing to pre-empt any decisions which may be imminent, you will appreciate my concern that there should be maximum co-operation with medical and social-work staff even at this early stage in order to achieve the optimal progress and quality of life in his present situation. I must stress again that I am in no way questioning the L.R.I. School's ability to make excellent provision for developmentally "normal" children. I would be delighted to discuss the matter with you at any time during normal working hours in the next three weeks.

Circular: Ten Discussion Points re. Special Educational Needs.

1. We feel that the question of educational provision for Oliver during the summer term should be sorted out as soon as possible, since other, fairly complex arrangements need to be structured around it. He will be returning home on the 28th March.

2. On the basis of visits already made, we are not convinced that there is any special school in the city which can adequately cater for Oliver's needs at this precise moment in time. We recognise that it may be impossible to achieve a perfect long-term solution given the accepted priorities in resource deployment, but in order to avoid possible disruption at a later stage we feel that the utmost care should be taken over deciding what is the most appropriate long-term provision. In view of this, placement may best be deferred until the beginning of the next academic year. Whatever the outcome of discussion, we may be eager to take advantage of our statutory right to comment on the draft of the statement of our son's needs together with other rights under the 1981 Education Act. We may also, if necessary wish to avail ourselves of the opportunity to view and comment upon any personal records appertaining to our child in accordance with the recent resolution of the Policy and Resources Committee.

3. Oliver's peak phase of alertness is during the morning session. Thereafter fatigue sets in. We feel, therefore, that any specific educational input needs to be concentrated in the morning. In view of this, school might not be the most appropriate provision at this stage. Pending further discussion we may be of the opinion that a home tutor should be made available for an adequate daily session for the remainder of this current academic year. This provision could be coupled with access for both tutor and tutee to the facilities of a "normal" school in the home locality in order to provide for social and other stimulation. This would be entirely appropriate to a post-Warnock situation.

4. While Oliver is now we feel certain, capable of sustained concentration during an entire morning session, it may be difficult for a teacher to sustain such a concentrated educational input on a one to one basis. Any one tutor would be in need of the support and guidance which teachers enjoy in

a normal school situation. We feel, therefore, that the optimal provision would be two tutors, each employed in the two two-hour sessions in the morning, with a half-hour "cross-over"/liaison period in-between. During this half-hour period Oliver would have a break between the hour-and-a-half lessons on either side while the tutors were planning/conferring.

5. Any tutor should be guided by the Schools' Psychological Service in the formulation and resourcing of an individualised learning programme which may take into account the following factors:-

6. [a] Oliver's hearing and aural comprehension is excellent. [b] There are problems with Oliver's vision. His perception of colour is very good, but with unfamiliar visual stimuli there appears to be a delay of some seconds in recognition. This should be borne in mind when using animated displays or scanning devices. [c] Oliver is proficient in the use of eye-movement [upwards], head movement, and indeterminate sound.

7. A co-ordinated, multi-disciplinary approach to the question of input controls to a Possum-type system should be tackled at the earliest possible moment. It is imperative that a more-than-rudimentary system of communication should be developed as soon as possible if Oliver is to make real progress. We cannot accept a constant deferment of this challenge. A system should be used and developed which lends itself to progression to increasingly sophisticated levels. There therefore needs to be close co-operation between teachers, psychologists, physiotherapists, speech therapists and occupational therapists. Who can, and will, take responsibility for this?

8. We accept that there is a possibility that there may be some permanent impairment of Oliver's ability to talk. There is, however, such a thing as "self-fulfilling prophecy". In view of his relatively advanced capacity to understand language and the inevitable psychological factors involved we will not accept any pessimistic diagnosis until we are convinced that every conceivable initiative and creative technique has been attempted and sustained for an acceptable period by speech therapists. We are aware that during the last three weeks Oliver's capacity to make meaningful vocal response has accelerated.

9. We wish to acknowledge that a major educational contribution has already been made to Oliver's progress by physiotherapists at the L.R.I. Quite apart from his obvious physical requirements, we that regular, preferably daily physiotherapy should be an integral part of educational provision, and special attention should be paid to the question of what strategies Oliver can employ to control or modify his environment and to communicate if he is to make real progress as a total person.

10. The "blob principle" must be avoided at all costs, especially when it operates at unconscious levels. Neither should the difficulties involved be inflated by bureaucratic ineptitude, lack of professional commitment, or covert discrimination veiled by the complexity of essentially political questions of resource deployment away from vulnerable minorities. Any "solution" which suggests that our son is less than a first-class citizen will be resisted vociferously by us in any way which seems appropriate. The painstaking nature of progress towards independence in the distant future should not provide an excuse for making inadequate provision in the immediate present. Education is one very important way of ensuring the optimal quality of life for this sentient human being now.



**Circular: "Towards a Programme of Curative Education". 1
April 1983.**

The following notes are not intended to be a definitive statement. We are aware that to many professionals involved with Oliver what we have to say may be "old hat" with "these kinds of cases", and some of our suggestions may appear to be unrealistic in terms of practice, or downright erroneous in the light of science. We would be glad to receive correction or further suggestions. Our main concern is that Oliver should be the object of a purposeful, integrated programme of treatment. We hope that this paper will initiate even greater discussion and communication between all those involved.

MEETING

During his times of alertness Oliver displays a high level of waking consciousness, but his periods of awareness have been shorter than the "average" person's, and he seems to drift between different levels of consciousness in a pattern which has not yet been closely analysed. In any case there are almost certainly psychological factors involved as a result of the accident, including the difficulty of evolving a new self-understanding. Oliver is a child who retreats into real or feigned sleep when faced with apparently insurmountable dilemmas or difficulties; there is every reason to suppose that as the trauma fades and he becomes physically stronger the present trend will continue and his periods of alertness will lengthen. The practical implications of this situation are as follows: [a] If Oliver's interest is sustained in the context of a caring one to one paedagogic relationship it is likely that the length of learning sessions will very gradually increase. [b] Oliver should never be stared at, manipulated without explanation, or spoken about in his presence without due deference to his awareness of what is being said. [c] Eye-contact at close quarters, possibly reinforced by physical contact, may be desirable as long as a "natural" manner can be maintained.

TRUSTING

As in the case of a "normal" child, a trusting relationship with familiar mentors is essential if Oliver is to develop social intercourse. The abilities which we take so much for granted are impaired in his case not only by perceptual difficulties but

also by the reinforcement of residual psychological trauma by the oddities in the behaviour of those encountered by him. The situation is akin to E.T. encountering the human race on Hallowe'en! For this reason helpers should avoid "talking down" to him, raising their voices [Oliver is certainly not deaf!] or unnecessarily repeating sentences more than once. As in the case of any "normal" social relationship, humour has an important part to play in removing barriers. A patronising manner will simply erect them.

THINKING

Association of sensory inputs is crucial in the development of cognitive ability, even if no immediate reaction appears to be forthcoming. Guidelines to "effect", however, may be a relaxation of the limbs and rapid eye-movement. Both seem to be indicators of increased mental activity. Simple examples of associative exercises are: [a] Passive exercises or massage to the accompaniment of music; [b] Visual stimuli accompanied by spoken or taped narrative or sound effects; [c] Visual presentations involving textured objects or "speaking" displays such as "Touch and Tell" [Texas Instruments] or puppets; [d] Clapping or tapping of extremities to music. Permutations will vary according to the helper's style or temperament.

SEEING

Oliver's hearing and aural comprehension is excellent. His sight is not so good. There appears, however, to be some considerable potential in the development of this sense. Techniques which may be employed in improving his gaze are: [a] Images which are fixed in a certain point in his field of vision but in which certain elements move. Mobiles are a good example of this, although it is difficult to ascribe meaningful content to them. Glove puppets are better - especially since movement in this case can be reinforced by spoken commentary. [b] Images containing simple components which can be scanned, ie. friezes. These should encourage Oliver to perceive images of increasing complexity. Such scanning is all the better if it requires him to employ concurrent head-movement. Friezes which have sequential meaning [similar to cartoon-strips] may contribute towards his re-education in symbolic communication, including written language [which has a major sequential element].

LAUGHING

As already indicated, humour may be fundamental in the development of aural and indeed visual comprehension. It should not be fanciful to suggest that some basic preliminary research is needed into different levels of humour and the degree of mental sophistication involved. Oliver has a ready "sense of humour". The role of incongruity, paradox and word-play in stimulating cognitive development should be explored. [Oliver laughed spontaneously at the following joke: Q.: "Why can't a car play football?" A.: "Because it only has one boot." This indicates that he can understand puns]. "Fun", of course, increases motivation to learn.

SPEAKING

Oliver has developed a simple code of communication. Looking upward means "Yes". Turning the head means "No". Lowering the eyelids may mean "I don't know". Experience shows that Oliver is now so proficient in this code that he can express a range of emphases - the equivalent of spoken intonation. It is imperative that people involved in conversation with him should make every necessary effort to allow him to express preference by use of this code. The procedure is cumbersome but worthwhile. The alternatives are presented and explained to him. He is told that the alternatives will be repeated slowly and he is to "look up" at the alternative which he prefers. This technique means, of course, that helpers must themselves frame the alternatives when Oliver is indicating unhappiness or discomfort by his facial expressions. This can be frustrating for both parties. If for some reason preference is ignored or there is an urgent need which demands attention Oliver will resort to vocal expression - but only as a last resort. In deciding how to respond to such noises two considerations should be borne in mind: [a] Oliver is not "crying like a baby". This activity may sometimes be unreasonable, but is never irrational. [b] Oliver could once speak. To make inarticulate sound may be a degrading experience for him. At the moment he is unlikely to make voluntary sounds unless he feels some urgency. Any attempts at speech therapy must take these factors into consideration. Oliver may see vocalisation as "babyish". If his confidence is to be increased speech therapy may have to be conducted in conditions of complete privacy and the purpose of any particular exercise should be explained. It is unlikely that he

will "perform" publicly unless his activities in this area have an instantly perceptible meaning to the recipients of his efforts.

CONTROLLING

The ability to exercise some degree of control over one's environment is fundamental to human self-esteem. Any kind of sensory feedback to movement will affect Oliver's confidence and motivation. Furthermore, meaningful feedback to pre-meditated movement will undoubtedly extend the range of his consciousness. Since Oliver's movement is limited, electronic devices are crucial to his development. The technical problems of light-scanned displays, input controls and software need to be tackled vigorously. In this context the role of Possum systems and computers needs to be studied in an imaginative and courageous way. Possible areas of progress with regard to input controls may be: [a] Touch-switches operated by head-movement; [b] Joystick-mounted buttons operated by Oliver's right thumb; [c] Trigger-type mechanisms operated by his right index-finger; [d] Fist-held pressure-pads; [e] Infra-red beam switches operated by gross leg or arm movements. Simpler feed-back devices involving buzzers or lights may be developed into meaningful systems of communication. Environmental control systems related to Oliver's needs should be explored. In this respect cues provided by his own conscious or unconscious initiatives - and the degree of frustration registered by him - should be carefully noted.

PLAYING

There is no substitute for the stimulus provided by a peer-group. In placing Oliver in this context careful consideration should be given to the balance between mental and physical capabilities, sex, and age. In this respect, Oliver must be given time and space to express his own preferences.

CHANGING

It is necessary to conclude on an exhortatory note. Pity or mere verbal sympathy [as distinct from active empathy] are of little use to the Medhurst family, even if it has some therapeutic function for the purveyor. Any approach which confers on Oliver less than the dignity of a human being, a spiritual entity capable of infinite progress beyond the physical limitations

which are part and parcel of the human condition, will cause Oliver to "switch off" and will make his parents angry. A programme of education should aim, not simply at producing an economically productive worker, or some feeble shadow of a social persona based on a simplistic notion of normality, but a person made in the image of God with the freedom of defining for himself what it means to be fully human. In the face of Man's eternal destiny, the difference between Oliver and anyone who reads these words is infinitesimal. Unfortunately, in the face of society the gap is huge. Like all of us, Oliver must change; but so too must society. A society whose definitions of what it means to be human leads to the virement of resources away from certain human beings must be the object of radical re-appraisal. And the starting-point for change must be those who are in a position to make decisions, but who have not questioned enough their own priorities.

Letter to County Councillor. 8 April 1983

Oliver, our son, sustained a serious head injury on 17 August 1982 and spent seven months or so at Leicester Royal Infirmary. He returned home on 28 March as a disabled person and it is now a matter of urgency to put in hand major adaptations at his place of residence [42a Hobson Road, Leicester]. An application for an improvement grant has been submitted to Leicester City Council. This is being handled by home improvements officer Mr. R. B. [Ext. 6841]. Various alternatives have been discussed with representatives of the County Council Occupational Therapy Dept. - principally Mrs. J. W. [Ext. 7284] but also Mrs. P. K. and Mr. S. K. We have had no personal contact as yet with the Principal Occupational Therapist Mrs. E. Z. A preliminary plan has been prepared by Mr. L. J. C. [864193]

Three issues are currently causing us some concern:-

[a] It has been suggested that a shower be installed as a permanent fixture in the new bathroom. On therapeutic grounds, as well as on the grounds of family convenience and ergonomics, we favour the semi-permanent installation of a Parker bath on a loan basis from the County Council. We have been told [in apparently *ex cathedra* statements] that the County Council would be unwilling to purchase and lend out a Parker bath on grounds of expense. But it should be borne in mind that the installation of an appropriate shower unit on an upper

storey would probably involve greater expense to the City Council - and possibly to us personally in view of the ceiling on improvement grants. We believe that the appropriate arrangement should be made with the domestic needs of the disabled person as the sole criterion. We do not wish to fall victim to a financial demarcation dispute between the City and County Councils.

[b] We have been told that we will be expected to defray some of the cost of the adaptations from our own pockets. If this is correct we must know at the earliest possible the expense involved and how our "share" is decided. Clear guidelines should be available regarding local interpretation of the Chronically Sick and Disabled Persons Act.

[c] It has been suggested that it may take a year or more to effect alterations. In view of the physical effort currently involved in caring for our son - which the adaptations are supposedly aimed at alleviating - this time-span would be intolerable.

Please do not hesitate to contact us or any of the above-mentioned officials directly if you require further information. Meanwhile, your assistance in bringing about a satisfactory solution would be greatly appreciated.

Contact Book [Ashfield School]. 11 April 1983.

Don't forget that it is Oliver's left side which appears to be most impaired - although he was previously left-handed. He can move his right thumb up and down [equipment enclosed]. Is this any use? He came home in a very good mood [after an anxious day yesterday] - but retired early!

Contact Book. 12 April 1983.

Slightly worried. After an intensive feeding programme over the holiday he seems to have lost his appetite again and to be losing weight. How is he eating at lunchtime?

Contact Book [Ashfield School]. 13 April 1983.

Owing to the fact that in the last few days Oliver's routine - ie. patterns of sleep, meals, physio. etc. - has gone "haywire" it

now seems impossible to predict bowel movements as promised. Your guess is as good as ours!

Contact Book [Ashfield School]. 18 April 1983.

Oliver went to Paul W.'s birthday party on Saturday. His sister looked after him while he was there, so we're not sure what he got up to. Later he listened to Paul's sister play the piano and had a "plonk" himself. Listened to a tape-reading of "The Wizard of Oz" yesterday. Oliver hasn't wee'd since yesterday morning so we've left his appliance off this morning. We enclose a couple of pads - I'm afraid he'll have to be changed once or twice during the day. For various reasons we have cancelled a hearing test which Oliver was to have had at the hospital today.

Contact Book [Ashfield School]. 19 April 1983.

Oliver will be attending physio at the Infirmary after school on Tuesdays and Thursdays (except this Thursday when Dr. M. will be coming). I aim to collect him at 3.45 p.m. for an appointment at 4.00 p.m. I am only able to transport him in his "buggy". I suggest that we continue to send him his Avon chair on Tues. and Thurs. together with his collapsed buggy. If Oliver can be transferred to his buggy by 3.30 p.m. ready for collection by me his chair can then be transported home (sans Oliver) in the usual way.

Is this complicated enough for you?!

We forgot to mention that Oliver bought a puppy last Saturday. It's a tricolour (ie. whit, black, brown) Cavalier King Charles Spaniel called "Lottie" ("Charlotte" actually!). She enjoys sitting in Oliver's lap but can be a greedy nuisance when he's eating. She hasn't been toilet-trained yet and keeps chewing things. I enclose a "What-o-Mess" tape - several stories on each side - which you might like to borrow for a while. Oliver has heard the stories once or twice but we haven't discussed them with him.

Contact Book [Ashfield School]. 24 April 1983.

Oliver has had a busy week-end. On Saturday he visited a riding-school with Mrs. Rees and saw some ponies. He's also been out twice in our new red car.

Oliver has sore shoulder-blades. Is there any way we can take pressure off his back?

Contact Book [Ashfield School]. 26 April 1983.

Oliver slept on his tummy last night and will do so tonight. We have a wedge at home but we use it sparingly since Oliver doesn't seem terribly happy on it - partly, I guess, because he gets bored: we haven't yet been able to devise a worthwhile pastime for him in this position!

We are generally concerned about Oliver's posture - he seems to be developing a stiffness in the hips as well as the knees and is clearly spending too much time in a seated position. I suspect that the friction sores on his shoulder-blades may be due to his tendency to slide down (when not in his Avon chair) or sideways into his habitual "banana" shape.

Our own feeling is that the solution is a mobile manual tilt-table normally at 45 degrees but regularly adjusted to shift the centre of gravity. This would solve all of these problems (we think).

I wonder if you could draw the attention of Mrs. M. to these notes today? I would be glad to hear any comments. These matters are of particular urgency in view of the fact that we have had to abandon physio at the Infirmary until a more sensible arrangement can be made. On the positive side, Oliver appeared to enjoy swimming very much, but came home whacked.

N.B. We need:-

- (a) mouth-care sponge-sticks (urgently)
- (b) penile-appliance condoms
- (c) urihesive strips
- (d) Downs catheter drainage-bags (small)

We enclose a "Touch & Tell" toy which Oliver or other children might find usable. Return in due course.

Letter to the City Council Housing Officer [Mr. J. C.]. 27 April 1983.

You will be aware that as a result of our son being severely disabled by a road traffic accident we have applied to your department for assistance with necessary adaptations to the above residence.

On three separate occasions we have made an appointment to see Mr. R. B., the first being on the 30th March. At the last meeting on 20th April, at which Mrs. J. W. from Social Services, and Mr. A.L.C. - the person responsible for drawing up plans - were present, it became painfully obvious that little or no progress had been made during that month in the consideration of our application. I say "painfully" because of the severe constraints and difficulties under which we are now labouring in the care of our son.

It became apparent during the course of our very brief conversation with Mr. B. that he himself felt unqualified to initiate progress towards a decision without consultation with senior officers in view of the discretionary element involved. I therefore formally asked him to arrange an appointment for me to meet and discuss the matter with you. I note with regret that you have not responded to my request in the course of the last week.

I therefore reiterate my request for an appointment to discuss the matter with you at your earliest possible convenience. I am confident that I do not need further to impress upon you the urgency of this matter and the cost of delay in human terms.

You will note that I have forwarded a copy of this letter to the local government ombudsman. I am concerned that we should not fall victim to the assumption by either the City Council or the County Council that actions by another Council may relieve them of the responsibility of themselves reaching any kind of adequate decision.

This kind of shuttle appears to have been already initiated in view of Mr. B.'s comments to Mrs. W. at the aforementioned meeting, and the consequent delays are causing us a great deal of concern and inconvenience.

Letter to the Schools Medical Officer [Dr. S.]. 27 April 1983.

Thankyou for your important initiative in arranging physiotherapy sessions at the L.R.I. on Tuesdays and Thursdays at 3:45 p.m. Unfortunately, our fears about the difficulties involved in availing ourselves of whatever facilities which may be available to us in the wider context of the community - as we expressed them in the last case conference - have in this respect been fulfilled.

To convey Oliver to the original appointment was impossible without consistent absenteeism from work. It did not seem possible to arrange a worthwhile session beginning after 4:00 p.m. After two attempts to travel from work to Ashfield School to the Leicester Royal Infirmary between 3:15 and 4:00 p.m. it became apparent that this too was impossible. There are no alternatives to this. Although Mrs. Medhurst is available from 1:30 p.m., she cannot drive; neither is she capable of handling Oliver single-handedly. We have therefore had to renege on the agreement.

It was, I must add, particularly frustrating to attempt the conveyance of Oliver to the L.R.I. in the knowledge that there is a well-equipped hospital a stone's-throw from the school!

I do not have to impress upon you the urgency of Oliver's needs and the observable deterioration that cessation of treatment entails. I would be very glad if you would help us to explore the possibilities for an alternative arrangement.

Contact Book [Ashfield School]. 2 May 1983.

Oliver's pressure-sores seem to be clearing up now. We think we have traced the problem to a nylon anti-smother pillow. We had used this to pad Oliver's back when seated because it was slim, and under his face for obvious reasons. Experience has shown that Oliver is strongly allergic to nylon shirts.

Oliver has been having a lot of fun with a tape-recorder and his sister who has been giving him crazy interviews. She seems to be able to elicit quite a degree of vocal response.

This afternoon we took him to see E.T. at the cinema - and he fell asleep ten minutes after the start and didn't wake up again until we left!

We played with the Atari video-games again to-day. Oliver's favourite is an aerial combat game because he can fire the machine-gun with his thumb.

I shall be ringing Mrs. G. on Tuesday morning to confirm the new arrangements for physio.

Contact Book [Ashfield School]. 3 May 1983.

We have left Oliver's penile appliance off again today. Can you suggest a significant time to set the musical alarm on his watch?

Contact Book [Ashfield School]. 3 May 1983.

Thankyou for the photos - lovely!

Contact Book [Ashfield School]. 11 May 1983.

We have given Oliver a rest today from his penile appliance - so look out for dampness!

Contact Book [Ashfield School]. 15 May 1983.

To-day we went to visit some friends who live in the country. They have a baby called Ben and two dogs called Bracken and Clover. We took Lottie with us and she kept following Bracken around because she's a spaniel too. We visited a place where they fly gliders in the afternoon. We watched an aeroplane tow a glider into the air.

Yesterday we visited the new toy shop where Mummy works - they've moved from the old one in Silver St. to a "new" one in High St. This was after a very boring afternoon in which Oliver watched me mowing the lawn and digging the garden while we played the songs from "Joseph and his Technicolour Dreamcoat" (Oliver knows a few of these songs from his old school).

Oliver went to church last week but he "skipped it" this morning because of the busy day.

Contact Book [Ashfield School]. 16 May 1983.

Read a story to-night from "Mice and Mendelson" in which characters speculated about what the moon is made of - cream cracker or silver shilling? Agreed in the end it was made of ice cream.

Blissymbol flash-cards in Oliver's bag - please return. Are they O.K.?

Letter to Leicester City Housing Dept. (J. C.). 17 May 1983.

Thankyou for your letter dated 12 May 1983.

I very much regret that you have refused my second request to discuss with you the requirements of our son, and the length of time it has taken for you to reach this decision.

I can assure that I do understand your duties as a public servant. In view of this I was very surprised to learn that you regard yourself as in a position to "make a decision". I understood that you were in a position only to make recommendations to duly elected bodies.

Although I am personally concerned by your refusal to gain first-hand information, I will assume that you now regard yourself as being in possession of the facts necessary to make a recommendation that will bear public scrutiny.

In view of your handling of the matter so far I am not entirely convinced of your goodwill towards the disabled community in Leicester. In view of this, I would be very grateful if you would send me a written summary of your recommendations as soon as you can bring yourself to make them so that representations can be made to the appropriate bodies before a decision is reached.

Since your conduct in this matter has broader implications regarding the rights of disabled people. I can assure you that the necessary action will be taken at all levels to ensure your department's policy comes under the closest possible scrutiny in order to facilitate the wide public debate which I shall be initiating should you continue to handle our case in an unsatisfactory manner.

Contact Book [Ashfield School]. 18 May 1983.

We have left Oliver's penile appliance off today.

His face is slightly sore after sleeping on his tummy – yes, we did use a sheepskin!

Contact Book [Ashfield School]. 22 May 1983.

We took Oliver "round town" yesterday, and had afternoon tea in Fenwick's. Then in the evening we went out and left Oliver with Mrs. T., our cleaning lady. He likes her company, and insists we leave him to fall asleep on the sofa while we're out. Today we had grandpa for lunch (as always on a Sunday) and then we went round to his house in the evening - he lives just around the corner.

It's been very quiet at home this week-end – Rebekah's been away visiting a friend.

Contact Book [Ashfield School]. 23 May 1983.

We enclose a facial massager. We chose this one because it had a wide variety of attachments. It seems a bit weak. (Is it the batteries? - we inserted some loose ones which were to hand). We suggest the following additions to Oliver's repertoire:

Grandpa

Television

Tape (recorder)

Story (book)

(Video) game

Cat

Meal: breakfast

lunch

tea

Hot - heat - fire

Cold

Sweet

More (adj.)

Wet

Dirty

Position/posture

Change (vb.)

This is not in priority order!

Contact Book [Ashfield School]. 24 May 1983.

Would you please be good enough to change Oliver's jumper before the end of school so that he's presentable for physio?

Contact Book [Ashfield School]. 31 May 1983.

Thanks in anticipation for the duplicate Blisschart frame.

It has been a chaotic four days in which we haven't done anything in particular except have a stream of visitors - including Oliver's cousin Alexander today who lives in London, and his "uncle" Peter last night who lives in Wales, and Mrs. Townsend on Saturday afternoon and this morning various children.

He did some painting this morning in the garden with his sister and caught the sun on his face. He slept a long time this afternoon and stayed up late this evening - just a little anxious about his stay at school.

Oliver has a new school-bag: the red-and-black striped case. His clothes etc. should be kept in the haversack. We will visit on Thursday afternoon after school. (Oliver has in any case to see Dr. M. at 3.30 p.m. Could someone ring the physio dept. at the Infirmary to tell them he's not coming?).

We shall be very glad of the rest over the next few days - Mum has developed a back-ache and I have a cold! I shall be at home all day Wed. - Fri. Give me a ring (65710) if you need anything for Oliver.

Contact Book [Ashfield School]. 5 June 1983.

Yesterday we took Oliver into town and had tea in Brucciani's. We bought him a racing-driver's crash-helmet to wear in the car!

This morning Oliver went to church and kept making noises during the sermon (I was preaching) - much to Mum's embarrassment!

He can't wear his appliance for a day or two since we've run out of urihesive strips. A prescription hasn't yet emerged from

the G.P. Oliver is now taking two Baclofen tablets at a time (ie. 20 mgs. three times a day).

We would be very grateful indeed if you could arrange to take him for his X-ray at 2.00 p.m. on the 10th.

We haven't mentioned to Oliver yet the possibility of his staying at school next week. We'll break it to him gently towards the end of this week. P.S. Mr. D. enquired about his musical watch. We'll try to remember to put it on him this week.

Contact Book [Ashfield School]. 8 June 1983.

We forgot to say that we have to take Oliver to the Red Cross Medical Aids Centre to-day to look at bathroom aids. Could you possibly keep him until 4.15 p.m. or thereabouts? - and send his Avon chair back on the bus?

We enclose some extra trousers and incontinence appliances (but no Urihesive strips!).



Circular. 9 June 1983. Residential Care

In the course of the last week on several separate occasions it has been suggested by various health service professionals that we as a family might benefit from Oliver being placed in residential care (ie. in a residential school or in a residential unit of a day school) on a permanent or intermittent basis. Since we have not been party to any formal discussions or consultations in which all relevant issues have been raised, we feel that it is necessary to express our own point of view before what we see as a relatively hand-to-mouth approach becomes established by default.

At the outset we would wish to discount the idea of a permanent residential education for our son for the same reasons that we would wish to discount it for our daughter. This is ultimately – or should be ultimately – a question of educational philosophy and other values which it would be fruitless to discuss in this context. In any case we believe that the benefits in terms of treatment which are discussed below would be far outweighed by the emotional and psychological dangers – however attractive the "solution" may appear to a health service which is unable to meet its responsibilities

There are two considerations with regard to intermittent care which should not be confused:-

1. Intermittent care can provide Oliver's parents with a much-needed rest from time to time.

This is certainly true and we are very reassured by the existence of excellent facilities at Ashfield School, and if a permanent placement is made we would very glad to avail ourselves of these facilities from time to time. Unfortunately times of more intense stress are likely to occur during school holidays and we have to explore the possibilities of other institutions such as Charnwood House. This fact leads us to the most important point: that respite care should be provided in the context of a flexible but carefully thought-out programme in which the "disabled family" can identify and express its own needs. The tendency to assume that a handicapped person, or, in the case of a minor, "handicapped parents", are incapable of assessing their own situation and initiating appropriate action leads to increasing dependency which is, we believe, entirely counter-productive. It would seem, therefore, that in the absence of any one person who is continuously and intimately

aware of the family's needs, the influence and decision-making capability of parents should be paramount. The challenge inheres in the establishment of streamlined consultative and decision-making procedures in which parents can be fully involved without feeling themselves under pressure.

Emotional pressure on parents may, of course, come about as a result of confusion of aims and criteria in making decisions. It is important in view of this that the needs outlined above should be kept separate from the second consideration which needs to be borne in mind:

2. Residential facilities can provide treatment not available at home.

This consideration is particularly relevant to the current shortfall in the provision of specialised physiotherapy for Oliver. Without deluding ourselves as to the magnitude of the task, and trusting in the effective implementation of measures by the social services, we believe that in all other respects the care provided for us for our son at home is qualitatively better than could be provided within an institution - except, of course, for those particular educational services available within a special school. In view of this fact, specialised physiotherapy is best provided at home or at school. A brief period in residence is undoubtedly a valuable procedure for assessment of Oliver's ongoing needs in this particular area, but should in way be regarded as a substitute for a programme of long-term treatment.

The above-mentioned shortfall is a source of profound concern to us. We are of the considered opinion that Oliver's entire needs are not currently being met. The health service needs, therefore, to consider one, or both, of the following measures:

- (a) Daily physiotherapy on a domiciliary basis;
- (b) Daily physiotherapy at school.

We are compelled at this point to make the general observation that one physiotherapist for a school of the size and nature of Ashfield is totally inadequate. Refusal to face this fact is to collude in the acceptance of an inexorable deterioration in our son's physical condition and an unacceptable burden on the integrity of the member of staff involved.

On a personal note, it is particularly vexatious to us when, as has happened on at least one occasion, discussion of this issue has been fudged by shifting ground to the first observation above. We will not, as a matter of policy rather than of pride, tolerate any suggestion that we are unable to "cope" when it is used to evade this apparently uncomfortable question.

The Community Health Council will, we trust, shortly be sending us a written report on physiotherapy services available. In view of the broader issues involved we shall, if necessary, wish to express concern in the strongest possible terms at all appropriate levels in the community, the health service, and the political system. We certainly have no objection to this document being made more widely available in order to initiate a broader debate. Meanwhile, we hope that the comments contained within it will clear the ground for any further discussions regarding the appropriate institutional support available to us in the continuing care of our child.

Contact Book [Ashfield School]. 9 June 1983.

"The Leicester Trader" may ring the school. They want to run a story on Oliver in connection with a police dog who visited him in hospital. I don't know if you have any contacts with the police, but I'm afraid we'll have to leave it up to you. We have no objection to this kind of publicity (provided we can check the reports for accuracy, but you may not like the intrusion - in which case send them off with a flea in their ear. Any queries ring me on Earl Shilton (93) 45061.

There seems to be rather more movement - probably involuntary - in Oliver's right hand lately ie. extending the fingers. Any suggestions to develop this? (Oliver can apparently now move the little finger on his right hand at will.) Incidentally, do you know if Possum have been contacted for a possible assessment *vis-a-vis* input controls? If not I'll contact them directly.

I was very interested to hear of the "drawing machine". Is it a mechanical device or something along the lines of a computer "turtle"?

Can you please confirm whether or not Oliver will be in residence next week? - don't worry: we agree to this in principle!

Contact Book [Ashfield School]. 13 June 1983.

Oliver is constipated.

We have sent in some fresh orange juice which we give Oliver first thing in the morning - he wakes up very thirsty.

Contact Book [Ashfield School]. 19 June 1983.

Oliver has eaten like a horse since he came home on Friday. We went into town yesterday - tea in Fenwick's - and we had friends round for tea today. We went to the swing-park this morning. Lottie chased round trying to catch up with us on the roundabout, and Rebekah showed Oliver how useless she is at tennis. He hung upside-down with his legs over a climbing-frame and we went down the slide a couple of times. Unfortunately, Oliver caught the sun; I expect his face will still be sore tomorrow.

We are sending in some "pop-up" books which are marvellous conversation-pieces. You may want to keep them for a week or two.

We hope to get along to the parents' evening on Wednesday.

Circular. 21 June 1983

Towards a Programme of Curative Education Phase II: Some Specific Recommendations

Physiotherapy

1. That the A.H.A. finance a two-year programme of 500 one-hour sessions of physiotherapy conducted at Oliver's home and/or school (ie. 1 one-hour session per week-day).
2. That the personnel involved should be provided with the necessary support and advice in the planning and implementation of such a programme.

Electronic Communication Aids

1. That the D.H.S.S. provide a portable Possum-type communication-aid for Oliver's specific use at home and school, accompanied by a range of appropriate interfaces.
2. That the D.H.S.S. finance any adaptations to equipment, or the provision of any equipment available from suppliers other than Possum, specific to Oliver's needs.

Education

1. That the L.E.A. provide a teacher on a supply/ home-tutoring basis for three 1 1/2 hour sessions for the duration of the Autumn term 1983 for the specific purpose of instructing Oliver in the Como eye-pointing programme.
2. That the L.E.A. sponsor an in-service training programme in the use of Blissymbolics with a view to providing support for the use of Blissymbols in Oliver's education and in the education of other non-verbal handicapped children.

Finance

1. That in the absence of financial support for the above recommendations from statutory bodies, and these bodies having given an unambiguous declaration of their position, all persons involved in Oliver's rehabilitation lend their support to an appeal for donations addressed to the public for the financing of any or all of these recommendations.

2. That the appeal be launched to span the first anniversary of Oliver's accident (17 August 1983) and his 10th birthday (10 September) - his 9th birthday having been passed in a coma.

Contact Book [Ashfield School]. 21 June 1983.

I'm sorry: owing to the unusual nature of the past week we haven't been able to rehearse Oliver's three new Blissymbols. But we have managed to make out some more flashcards.

Contact Book [Ashfield School]. 23 June 1983.

Thanks for the postcard of the town called "Oliver".

After a "lecture" from his Mum about talking Oliver surprised us both by starting to move his tongue backwards and forwards. With a lot more practice we're sure he'll soon be able to stick his tongue out at you! Despite the anti-social overtones we'd be glad if you would encourage him.

Have a good time at Alton Towers. Phew!

Contact Book [Ashfield School]. 26 June 1983.

Yesterday Lottie was yelled at, smacked, and put in solitary confinement (the garage) for stealing and devouring a stick of Oliver's rock from Alton Towers. She was incriminated by her evident stickiness. Poor old Oliver didn't know whether to laugh or cry - so he did both! This afternoon we went to Abbey Park. We visited Pet's Corner and saw some of the peacocks showing off.

We'll make an inventory of Oliver's equipment before Friday. We were interested in the prone table (ie. when we came on parents' evening). Could we borrow it over the holiday? We have a carpenter friend who might be able to make a Mark II with more leg room. Has his leg-brace been sorted out? Does he wear a collar? etc. etc.

Contact Book [Ashfield School]. 27 June 1983.

We could collect the prone-board etc. at around 4.00 p.m. on Friday - or any day previously in the evening. We have indeed thought over Dr. Chan's "ideas". Subject to a re-assessment

when we saw him again on 5th Sept. (2.45 p.m. at the General) we have decided not to use the body-support. We are convinced that there must be a more creative solution. How about sleeping on his left side in a hammock?! Anyway, we'll think further We're sending in for a few days joystick-type control that was made specially for Oliver to experiment with. It plugs into an Atari video-game system like the one at school. Oliver enjoys playing game no. 18 on the "Combat" cartridge. If you have time, could you encourage him to use it? – particularly in pulling it towards the second switch. I'm afraid one of the wires has come adrift from the plug. (I don't know how to solder!). You can see where it goes from the tiny dab of solder; just push the wire in.

P.S. Please congratulate Oliver. The little finger on his right hand is moving even better.



Circular. 1 July 1983.

We hope that this document will be construed as a positive attempt to overcome the first problem. We believe that a frank statement of our own attitudes will remove the obstacles of misunderstanding and clear the ground for a genuine open dialogue in which no individual regards himself as having a monopoly of wisdom. At the same time, we see the proposals set out here as our contribution to the establishment of an integrated programme of curative education which will be genuinely helpful to those who are concerned with Oliver's future.

PROPOSALS

A Basis for Progress

1. As Oliver's parents, our "territory" inheres in his entire being as an emotional, physical, intellectual and spiritual entity. We therefore see our role as crucial in the establishment of an overview. Even if rigorous division of labour hardens into the professional orthodoxy we will never accept any diagnosis and proposed course of treatment which does not take into account other elements in the total picture as adequate. We would wish to see established, therefore, a more streamlined system of consultation in which there would be a freer flow of oral and written information and a frank and open exchange of opinion.
2. We have every reason to believe that Oliver will be early in reaching puberty.

In any child, the pre-adolescent stage, in which mental and physical growth are rapid, and in which processes occur which are unrepeatable, the foundation is laid for the difficult emergence into adulthood. In the adolescent phase the child himself must participate in the evolution of his own destiny - a fact which a parent may view with consternation. While adults may often find themselves helpless during the child's puberty, they have a decisive role to play in nurturing the child's identity and potential in the pre-pubescent phase. We therefore see the next two years between Oliver's tenth and twelfth birthdays, as absolutely crucial to Oliver's future life. We would wish to see established, therefore, an intensive two-year programme - a kind late primary "Headstart" - of education and therapy aimed at directing Oliver's physical and mental

growth and equipping him with the basic for him to explore and express his full potential in later life.

Physiotherapy

The enormous degree of physical activity engaged in by the "average" nine-year-old contributes in a major way to the development of a "normal" physique. Such activity is beyond Oliver's reach. Besides facilitating any possible recuperation of muscular function - and the rashness of predictions regarding the extent of Oliver's natural recovery has already been proven - and generally safeguarding his general level of health, specialised physiotherapy (as distinct from "passive movement") is essential in preventing progressive distortions in his posture and physique. If our responsibility to Oliver in this area is not met, then neglect could have far-reaching consequences to his appearance - a critical factor in his social acceptability - and to his potential for training towards independence at a later stage. The suggestion that we should implement such a programme ourselves is unrealistic in its assessments of the demands upon our time and energy and dismissive of the specialist skills of the qualified and experienced physiotherapist.

We therefore propose:

1. That the A.H.A. finance a two-year programme of specialised physiotherapy consisting of 500 one-hour sessions conducted at Oliver's home and/or school. This means, in effect, one hour-long session per weekday for the next two years.
2. That the personnel involved should have access to the necessary support, advice and consultative procedures in the planning and implementation of such a programme.

Electronic Communication Aids

It has been suggested that "Oliver is not ready for this". We agree. It is precisely because we do not expect him to wake up one morning and find himself capable of using a possum typewriter that a period of initiation and training is essential. Suitable equipment must be acquired soon so that over the next two years Oliver can become highly proficient in the drills and procedures necessary for their operation. He has a great

deal to communicate now. By the time he has mastered these procedures he will be able, we hope, to embark on that struggle for self-expression which is so fundamental to the dignity of a human being. The urgency with which children at the primary level are encouraged to acquire literacy skills is entirely applicable to Oliver, however broad our interpretation of "literacy".

We therefore propose:

1. That the D.H.S.S. provide a portable possum-type communication aid for Oliver's specific use at home and school, accompanied by a range of appropriate interfaces.
2. That the D.H.S.S. undertake to make any necessary adaptations to such equipment or to purchase, if necessary, equipment from suppliers other than Possum.

Education

The Blissymbolic system provides an important framework for Oliver's cognitive development and, at a more mundane level, day-to-day communication. Even if Oliver is able to develop efficient usage of electronic aids, the flexibility and autonomy of eye-pointing techniques means that they will continue to be the basis for most of his social interaction. With a great deal of foresight and enthusiasm Oliver's speech therapist has already initiated a learning programme; but other demands on the therapist's time and the importance of the system to Oliver's overall education make extra input essential.

We therefore propose:

1. That the L.E.A. provide extra teaching-support for a limited period (at least one term) for the implementation of an eye-pointing programme related to the broadening of Oliver's Blissymbol vocabulary under the supervision of the speech therapist. It may be desirable to back up such support by the provision of a modest programme of in-service training for the teacher involved.
2. That the L.E.A. purchase and provide on a loan basis the range of equipment necessary for the implementation of such a programme.

Finance

If the relevant statutory bodies are unwilling to make the necessary financial outlay to support the proposed two-year intensive programme we intend to seek public support. We believe that an appeal is best initiated during the period 17th August - 10th September 1983 to be concluded at Christmas 1983. (17th August 1983 is the first anniversary of Oliver's accident. 10th September 1983 is the date of Oliver's tenth birthday. is ninth birthday was spent in a coma.) The funds would be administered by a trust and vired to the areas of unmet need. Since any such appeal would inevitably involve the co-operation of the media it will be difficult to control its impact on those institutions directly involved in Oliver's welfare. We hope that such institutions will nevertheless view such an appeal sympathetically and regard it positively as an attempt to supplement the excellent services which they are providing. In particular, we hope that Ashfield School will be willing to accept par contributions from individuals or corporations and to tolerate the concomitant publicity which may be desired by the instigators for other than altruistic motives!

In order for such an appeal to be possible it is necessary for us to receive a definite response to our proposals by the end of July 1983. We realise that the Health Service will be wary of any adverse publicity that may accrue to a categoric refusal of services, but we hope that the individuals involved will put Oliver's welfare before their own real or imagined "image".

Conclusion

We conclude our proposals with a plea for understanding. Although we are absolutely committed to caring for our son at home, in the belief that the optimal development of his potential can only come about within the context of a strong and caring family, we do not underestimate the difficulties involved in marshalling the appropriate support, nor do we denigrate the work which has already been done. We particularly appreciate the care and creativity displayed by some professionals in taking initiatives which have entailed extra work for them. Having said this, however, we beg those in a position to make decisions to consider the following facts:-

1. There is a limit to our time and energy. Even if we had the expertise it is difficult, considering the current demands on our domestic routine, to set aside a "slot" for any particular task beyond those essential in the parental care of a child, and to find the energy necessary to sustain extra input.

2. The health of the family as a whole is essential to Oliver's well-being. A routine which jeopardised our own physical health and led to the neglect of our daughter would ultimately be detrimental to Oliver.

3. Some types of input can only be effectively made with a degree of objectivity and detachment which parents in any circumstances would find it difficult to sustain. Being a parent has its own satisfactions, but the role is sometimes incompatible with techniques which must be used to get results.

We have the will to overcome these difficulties. We are asking for a comparable measure of goodwill from the caring services - both for the sake of Oliver, and for the sake of future victims of traumatic brain-injury for whom provision may still be regarded as on its infancy.

Contact Book [Ashfield School]. 1 July 1983.

Inventory:-

Avon chair

Tray

Joystick and bell

Custom joystick

Four "pop-up" books

Prone-board (loan)

I will collect at 4.00 p.m.

Letter to the Chairman of the Area Health Authority (Prof. A. R. B.), 7 July 1983.

We are taking the unusual step of writing to in order to clarify for ourselves the overall strategy in the treatment of our son during the next two years. This overture is in no way meant as an attack on the professional integrity of anyone currently engaged in his treatment. But we feel that, owing to the difficulties of prognosis in cases of traumatic brain injury, and to the scarcity of resources for the treatment of long-term patients living at home, opportunities for progress, however uncertain, may be overlooked.

As laypersons without medical training it is difficult for us to moot proposals with a trustworthy objectivity. But as the child's parents we entertain an overview of his total welfare which emboldens us to suggest provision which will, we believe, "block in" elements within a total strategy for achieving his optimal well-being. We are aware of the financial and administrative pressures which make standardisation of treatment necessary, but you will be aware that the complexities involved in meeting the needs of a brain-damaged person make individual programmes imperative. We are therefore seeking to use what flexibility there may be within the health service to initiate discussion as to how far our son's potential can be explored and developed.

We are currently witnessing a deterioration in our son's posture which we will not accept as inexorable. Leaving aside the questionable functional capability of his limbs, we believe that his appearance is a crucial factor in his future social acceptability. We are certain that you do not need to be reminded of the importance of "cosmetic" factors in a patient's personal and social well-being. At the same time, we feel that our son should be maintained in a state of optimal physical fitness in order to maximise the potential natural recovery of limb-function. Regular physiotherapy is therefore essential. At the moment, owing to what we perceive as a shortfall in provision at Ashfield School, Oliver is not receiving regular treatment at school. We are also uncertain as to how far the two 45-minute sessions which he is currently receiving at Leicester Royal Infirmary can be, or will be, sustained. We believe that one hour of physiotherapy on each weekday sustained over a two-year period is the minimum requirement for this particular patient. If a doctor is willing to state in

positive terms that this is not a minimum requirement we would then re-consider our intention to question the current shortfall at all levels.

Our next concern is Oliver's potential for communication. We understand that Dr. Moore has initiated the process of application for a communication-aid and that our son is likely to be assessed for a P.O.S.S.U.M. typewriter in the near future. Once again, however, we find it difficult to see how the standardised provision - if and when it materialises - can be adequate to our child's needs in this area. We feel that a customised "package" needs to be assembled which provides a range of input controls relating to a system which utilises the most recent advances in microelectronics now available from a variety of suppliers. This challenge must be met sooner or later. We are asking the District to start here.

We realise that it is impossible to separate medical, social and educational provision. We hope that this will not, however, lead to demarcation of responsibility disputes between the caring services. You can be assured that we are making other, discrete demands on the Social Services and the Education Service. We feel that the issues outlined above fall squarely on the shoulders of the Health Service.

We must conclude by saying that if resources or services are not available via the N.H.S. to meet what we see as the minimum requirements outlined above, we must reluctantly explore other sources of help. In order to facilitate this, a categoric refusal of provision could be helpful. Since we hope to embark on a two-year programme in the autumn, in order to take advantage of our child's current developmental stage, it would be very useful if you could assist us in clarifying the picture in the next month.

Assuring you of our goodwill and active co-operation at all times . . .

Letter to the Adviser to the County Council on Special Educational Needs (Mrs. C. E. S.). 7 July 1983.

Thankyou for your letter of 21 April 1983 and its very positive response to our pamphlet "Towards a Programme of Curative Education". We found a great deal of encouragement in your offer to explore ways in which the local authority could improve the resourcing of our son's education.

As you are aware, as a result of his accident Oliver can no longer talk. His receptive capabilities, however, appear to be largely unimpaired. His eyesight, although it has improved considerably over the last few months is still affected in ways in which it is difficult to assess, but it seems likely that he would experience difficulty in using a written system, like the phonetic alphabet, which required rapid absorption of small, sequential characters.

In view of these problems, we believe that the Blissymbolic system offers the best vehicle for the continuation of Oliver's education. It is, however, an onerous task for a child to rapidly reach mastery of a system "from scratch" to the degree required to embark on a meaningful language-enrichment programme. A modest attempt has been made to begin teaching the system by Oliver's speech therapist, but the limited sessions available, and the other demands on time within those sessions, together with the very limited teaching materials at her disposal, makes it extremely unlikely that progress commensurate with Oliver's learning capability will be sustained.

We realise that the extent to which extra teaching-help may be available for a Blissymbolics learning-programme is potentially a contentious issue, but we are eager to know whether the County has invested, or is willing to invest, in materials and equipment specific to the Blissymbolic system.

We would be very grateful if you would furnish us with any information regarding the availability of such materials on a loan basis in this Authority. We appreciate that we may have to purchase such materials ourselves, but with there being so many demands on our financial resources at this time, we feel obliged to proceed with this enquiry.

We look forward to your continued support and active sympathy in the difficult months ahead as we seek to establish

the best possible individualised learning-programme for our child.

Letter to Occupational Therapist (Mrs. M. M.). 8 July 1983.

You will be aware that Dr. C. saw Oliver in the middle of June and will be seeing him at the beginning of September. As a result of his "advice" we have decided not to use a support jacket. This decision will be reviewed in September pending the result of a further X-ray.

We are now at the stage where a satisfactory seating-arrangement for Oliver is a matter of urgency. Please let us know if you need any further co-operation from us in moving swiftly towards the provision of a moulded seat. You will be aware that our solution to the problem of Oliver's vehicular transportation is largely dependent on the finished product.

Letter to the Occupational Therapist, Social Services (Mrs. J. W.). 8 July 1983.

Thankyou for your help so far; we look forward to further liaison with you regarding the programming of the adaptation-works to our house. As you know, we are hoping to move towards a long-term solution to Oliver's mobility problems. Towards this end we have purchased a vehicle which can accommodate a wheelchair. Until his individual conveyance problems are solved *vis-a-vis* an appropriate wheelchair, adaptations to the vehicle itself are not a matter of urgency. A solution to the problem of loading and unloading of Oliver in a wheelchair is, however a matter of extreme urgency. Our son is growing at such a rate that it is now no longer possible for one person to lift him without risking physical injury. This severely reduces his mobility.

We would therefore be very glad if your department would consider lending us a portable jack-hoist for loading and unloading a wheelchair. The purchase of the vehicle is a considerable drain on our finances; we simply cannot afford to deploy more of our thinly-stretched resources in this area.

We would be very grateful if you would advise us of the necessary procedures in submitting a formal application.

Contact Book [Ashfield School]. 12 July 1983.

Oliver has urinated into a bottle three nights running at bedtime.

Letter to the Principal Educational Psychologist [G. T.]. 14 July 1983.

Thankyou for your letter of the 13 July. We found our last meeting with you very useful and for this reason we look forward to seeing you again on 20 July at 3.15 p.m.

Your letter seems to suggest that you are only willing to share information with us as a result of the obligations imposed upon you by the 1981 Education Act and the legal framework provided by it. It would be helpful if you would confirm this in writing before our meeting so that our attempts to establish an open partnership with professionals beyond the terms of the Act can be seen to be, as we suspected, quite futile.

Yet again, as we seek to express our views, we are forced to state that we are in no way conducting an attack on anyone's professional integrity. We have no doubt whatsoever that "a lot of people are working very hard in Oliver's interests".

Please feel free to use our last letter in whatever way you think best in the furtherance of Oliver's educational interests.

Letter to the Assistant Director of Education - Special Needs [Mr. D. E. R.. 20 July 1983.

I am writing to ask for a full assessment (under Section 5 of the Education Act 1981) on my son Oliver, as is my right under Section 9 of the new Act. My son is currently receiving special educational treatment at Ashfield School, Leicester.

We trust that the process of compiling information for a formal statement of Oliver's special educational needs can begin forthwith. Mrs. Medhurst and myself look forward to hearing from you as soon as possible.

Circular to all representatives of the news media. August 1983.

THE HEADSTART FOR OLIVER PROGRAMME (H.O.P.E.)
and THE OLIVER MEDHURST BIRTHDAY APPEAL

Launch date: 17 August 1983. This is the first anniversary of Oliver's accident.

Oliver's situation has already received some media-coverage during the past year. Radio Leicester gathered together some of Oliver's friends to make a broadcast aimed at bringing him out of his coma. "The Leicester Mercury" ran a story about the impact of a police dog on his recovery. "The Leicester Trader" reported a farewell visit on the dog's retirement.

These stories generated a huge amount of interest. We received very many enquiries about Oliver's progress from complete strangers. These enquiries have convinced us of the enormous concern on the part of the public about his situation and have encouraged us to seek wider support.

We believe that Leicester would like to hear more about Oliver. We are willing to supply any information you require. In return, we are asking you to help us give details of the Appeal to the public at large. We are convinced that many people wish to help and would welcome the Appeal as an opportunity to make their own contribution. We hope therefore that you will send a representative to a PRESS CONFERENCE on Monday 15th August at the offices of the Leicester Diocesan Board for Social Responsibility: 278 East Park Road, Leicester (Room 6) at 2.30 p.m. Tea will be available. Oliver, his parents, his sister and the family dog will be at your disposal.

Please help us to get our message across. We are certain that the people of Leicester want to hear it.

Letter to the Director of Education [Mr. F.]. 12 August 1983.

Thankyou for your letter of 3rd August 1983 and the news of your proposal to assess our son's educational needs with a view to the possibility of making a Statement in accordance with the 1981 Education Act. We confirm that we are in agreement with such an assessment being made.

If you decide to go ahead with a full assessment we look forward to receiving a formal notification of this decision as soon as possible. We trust that you will then forward to us details of a named officer to whom we may go for further information, in accordance with Section 5 (3) of the Act.

The specification of a period of 29 days for comment in your letter of the 3rd August, however, suggests that this is to be regarded as formal notice of your intention to make an assessment. If this is the case, then we would be grateful if you would supply us with the name of an officer forthwith so that we can make the best possible use of the remainder of the specified period, in accordance with S. 5 (3) mentioned above. In particular, we would be grateful if you or the named officer would supply written answers to the following questions within the specified period:-

1. Do any reports already exist about Oliver? If so, can we have copies?
2. What advice does the authority intend to seek, and from whom?
3. Will those giving advice be provided with checklist contained in Circular 1/83, and what is the authority's attitude towards this checklist as a basis for advice?
4. What examinations will be required, for what purpose, by whom and where?
5. Will there be any case conferences and if so will we be informed and invited to attend?

In addition to a written reply to the above questions, we would be grateful if arrangements could be made for us to meet with the named officer within the specified period for a discussion about the availability of appropriate educational provision for

our son within the authority, in accordance with EA 1980 S. 8, Education (School Information) Regulations 1981 and Circular 1/83 para 20.

In conclusion, and on a less formal note, we wish to express our hope, that it will be possible to build up a relationship of complete trust with those who are concerned with making decisions which affect Oliver's future, and that this will enable us to fulfil the spirit as well as the letter of the law.

Contact Book [Ashfield School]. 15 August 1983.

Oliver is now completely "dry", even to the extent of being reluctant to use a penile appliance for convenience on outings. (He does, however, still wet when asleep - although he does "save" some for the morning). He urinates round about 10 a.m. and 1 - 2 p.m. into a bottle in a supine position. He indicates his desire to "wee" by a low moan which we're sure you'll soon pick up.

We went swimming last week at the Holiday Inn (Oliver is a member). His lack of control over self-immersion in the cold water makes him tense up, but for some reason he seemed a lot looser after a session in the sauna!

Oliver went to the Red Cross play-scheme twice, but his inability to participate in any activity (apart, perhaps, from playing with a remote switch-operated toy car) has convinced us even more of the urgency of developing input controls. Dr. M. tells us that Dr. M.-L. will be coming to assess Oliver - for POSSUM - in September. I have, incidentally, ordered some Blissymbol software for an Apple II computer.

A dentist (Mr. C.) has had a look at Oliver's teeth and will be fitting a brace in September.



Public Leaflet. 17 August 1983.

THE OLIVER MEDHURST BIRTHDAY APPEAL

Who is Oliver?

In August 1982 Oliver Medhurst was a normal eight-year-old boy looking forward to his ninth birthday and enjoying the summer holiday. Then disaster struck, and a month later Oliver spent his birthday in a deep coma.

Every parent's nightmare had come true. On his way back home from the corner shop Oliver ran out into the road and was struck head-on by a car. Witnesses say the driver was not to blame. His parents dashed to the scene to find their son gasping for life. The family was rushed to the Infirmary where it was found that, besides breaking both his legs, Oliver had sustained a serious head injury.

During the following weeks in Intensive Care the staff at Leicester Royal Infirmary were brilliantly successful in their struggle to save his life, but could not prevent permanent brain damage. Surgery at Leicester and later at Derby helped to minimise it, but no-one could be certain how long the coma would last

Three months later, as parents and friends lived through the agony of doubt and fear at his bedside, Oliver began to emerge from his twilight world. But his problems were only just beginning.

The Challenge

Thanks to the constant and devoted care of hospital staff and friends Oliver began to return to the world he had so nearly left for ever. Moments of joy relieved the seemingly unending darkness - like when a visiting police dog jumped on his bed, barked, and Oliver opened his eyes wide in boyish wonder; or when the shared reminiscences of his mum and dad were acknowledged by a smile - the first they had seen for months.

From that moment on, his parents knew that any attempt at stimulation, any contact with the real world, any therapy - no matter how unusual - was worthwhile. As friends prayed throughout the County, their prayers seemed to be being

answered. But it also became clear that God had set a task for everyone who cared - a task that demanded all the skill and patience of a midwife at a unique rebirth

What makes Oliver special?

Even when Oliver had "woken up", it was clear that he could not move or talk. In the early stages he could not even swallow. Gradually, he learned to take, chew and swallow solid food. Painstakingly he developed movement in his head and eyes. It became apparent that his left side was more affected than his right - as though he had suffered a giant "stroke". With the strength and determination that only a child has, his struggle to move an arm or finger continues - every week a millimetre more. He refuses to be "written off".

Most surprisingly of all, it has become obvious that Oliver understands everything that is said to him. He listens to stories. He enjoys music. He answers "Yes" by looking up and "No" by turning his head. He cries when something isn't "fair". He laughs at jokes. We thank God that his sense of humour is intact. The "old" Oliver is still very much with us. He still has the same likes and dislikes. He can still be naughty by refusing to eat his dinner, still win hearts by his melting smile and rolling eyes. Oliver is still a person. Like a secret treasure in broken but salvaged box his personality is still there to be cherished.

But we are left with a tantalising question which only you can help us to answer. How much progress can Oliver make before the vigour of childhood leaves him? And what sacrifices can we demand of the community at large to give Oliver that boost he now so urgently needs? Can you help us face this challenge?

THE HEADSTART FOR OLIVER PROGRAMME (H.O.P.E.)

Our aim is to provide Oliver with an intensive programme of training and therapy over the next two years. If he is to develop healthily in body and mind, he must be treated by experts and he must be given apparatus and the skills to use it. There are no "miracle cures". Oliver himself must do the work. It will be a long, hard slog. But we hope that with the right treatment and equipment Oliver, by the time he has reached his teens, will be able to begin the struggle towards independence.

The National Health Service has saved Oliver's life and set him on the road to recovery. But now that he has left hospital the few resources that the health service can provide are stretched to their limit. We need cash - to pay physiotherapists and teachers to pay for the use of facilities, to pay for equipment and to pay for special adaptations so that Oliver can use it. H.O.P.E. will be based on a three-pronged attack on Oliver's disabilities:

1. MOVEMENT

Oliver is effectively paralysed. He cannot do anything for himself. To prevent deformities as he grows, others must exercise him. It is back-breaking work, made even more urgent by the need to keep his limbs supple just in case he develops more movement. This is always possible as his brain heals and makes new circuits to by-pass damaged areas. But the wrong sort of exercise might do more harm than good. So we must pay physiotherapists to give skilled treatment and advise volunteers.

2. COMMUNICATION

Oliver cannot talk and he cannot write. And yet, before the accident, he had an above-average reading age. We must unlock the reading-skills gained in the last nine years and help him to develop more. You may have heard of P.O.S.S.U.M. (Patient-Operated Selector Control Mechanisms). The technology to help Oliver does exist, but it is expensive. And to help him to gain access to the world of electronics and micro-computers, special controls must be made to overcome Oliver's disabilities. So we must pay experts to build the right equipment.

3. LANGUAGE

"Speech plays a vital part in the organisation of complex forms of mental activity". This quote from an eminent psychologist can be put in plain English: if Oliver's speech does not develop, neither will his thinking. Although Oliver is beginning to make sounds, he will not be able to speak for a long, long time - if ever. Yet he has plenty to say. Blissymbols can help him to express day-to-day needs and be educated. The quicker Oliver can build up his Blissymbol vocabulary, the quicker he will progress mentally. So we must pay for extra tuition and teaching materials.

Oliver's parents are committed to caring for him at home, in a normal family atmosphere. There are some things which money cannot buy. But the stresses and strains of bringing up a severely handicapped child are enormous. Your contribution will help both Oliver and his family to survive and to flourish. Faith moves mountains. Let us have faith, not only in the cash, but the care and concern of the people of Leicester.

HELPING OLIVER: A SHARED ADVENTURE

The world is plentiful in suffering and scarce in resources to deal with it. Those who care about others and want to help them out in their troubles are faced with a dilemma: whom should they choose to help? Where will their contribution have the most impact? How will a donation get the most results?

In deciding whether or not to support H.O.P.E. We ask you to consider the following points:

1. Life is more than survival. The community as a whole, through the National Health Service, has enabled Oliver to survive. We are now asking you, by supporting our two-year programme, to improve his quality of life. This is usually a matter of choice for each individual. We hope that, with your help, Oliver too will have a choice as he overcomes his handicaps.

2. Oliver is in that rare category of children who suffered brain-damage in later childhood. We have nine years of "normal" childhood to build on, in which he learned to talk, read, and do things which other brain-damaged children cannot do. Oliver

is therefore in a unique position to help explore ways in which we can overcome major handicaps.

3. Unlike in the U.S.A., management of traumatic brain-injury in this country is still in its infancy. By helping us to work out and implement a programme of treatment you are helping us to show what can be done with other accident survivors. By supporting us, you may also be indirectly supporting other relatives in their struggle to get the best treatment for those they love.

There are many things which Oliver needs which money cannot buy. The new challenge facing him would be impossible without a caring family and a circle of friends in which, despite his strange disabilities, he can find acceptance as a child with the same hopes and fears as other children. But cash is important. **SHOW YOUR CONCERN BY GIVING US A DONATION TO HELP US PUT OUR CARE INTO ACTION.**

FIGHTING BACK. The Headstart for Oliver Programme (H.O.P.E.)

Published and privately circulated by P. & J. A. Medhurst in 1984

INTRODUCTION: THE BASIS OF DECISIONS

Multiply-handicapped children like Oliver do not belong to a different sub-species. The same educational criteria apply to them as to 'normal' human offspring. In the education of any child, the aim is to place before him a range of opportunities which will enable him to explore and develop his latent potential. It is a "leading out" (Latin *educare*). If a child is not to be educated for failure, it is necessary for the teacher to be at least one step ahead: to establish realistic goals related to the springs of the pupil's motivation, in the hope - and in the initial stages it is hope rather than certainty - that the young person will progress towards them. To adopt a static approach, in which it is automatically concluded that progress cannot be made to a further stage and the handicapped child needs merely to be occupied or entertained, is a betrayal of the most fundamental of educational principles.

The same criteria apply to therapeutic activity. There is a sense in which no human being is completely "whole". Yet therapy aims to lead the patient to wholeness. This is the essence of the healing art (Old English *hale*: "whole"). Once again, if the patient is to be dealt with rather than just the disability, the therapist must establish realistic goals related to the patient's optimum potential quality of life. To pursue a mere holding operation, in which it is concluded that the patient is simply a disordered body-mechanism whose condition can at best be prevented from deteriorating, and whose needs as a human being are confined to being kept "comfortable", is likewise a betrayal of the most fundamental of therapeutic principles. Even within the narrow parameters of orthodox medicine, such an approach to the management of traumatic brain-injury is medically unsound.

What every professional involved in "very special" education should be aiming for cannot be summarised too easily in a simple phrase. Because our expertise as Oliver's parents lies primarily in the educational field, we have tended to use the term "curative education". Had our expertise resided primarily in the medical field, we might have chosen the term "holistic therapy". Both amount to the same general approach.

For those involved in the assessment and statement of Oliver's needs within the terms of the 1981 Education Act and the consequent allocation of resources, financial considerations may be uppermost. In the present economic climate the setting of realistic goals - related to the "realities" of the child's needs rather than the "realities" of financial constraints - may be distorted by considerations extraneous to education and therapy. Decision-makers in both the health and the education services may seek to establish a pessimistic prognosis, thereby implying that the further investment of resources is futile. On the other hand they may proffer a glib, over-optimistic prognosis in order to justify a "wait-and-see" policy in which the pupil is expected to demonstrate ability and make progress in a vacuum. We have known the same professionals to veer between both stances in accordance with the demands being made upon their service. It is particularly unnerving - when so much is at stake - to encounter an administrator who has so lost sight of his or her priorities in the implementation of sound therapeutic or educational policy that the process has become unconscious.

The priorities of politicians involved in the formulation of policy and the allocation of macro-resources may also fall victim to false values. Those who would seek to sell our son's birth-right of human fulfilment for a mess of cost-cutting should understand that if education and therapy are costly, ignorance and illness are immeasurably more expensive. Cost must be measured in human as well as financial terms. The creative solutions are less expensive in the long run. A full programme of education and therapy is an investment in Oliver's future independence. Any measure of progress towards this is a long-term money-saver.

Politicians, professionals and administrators all need to be reminded that myopia induced by expediency may place on the fragile shoulders of a handicapped child struggling towards independent maturity the burden of their own inadequate perceptions. In view of these important considerations we have outlined a programme which sets realistic goals for Oliver and describes the means to achieve them. We have not balked at our responsibility for his future. We solemnly anathematise any attempt, conscious or unconscious, to undermine our sacred trust as we seek to deploy all available resources towards the realisation of our child's human potential. We invoke our son's unqualified right to be both accepted and welcomed as a full member of our community. In this sense, our proposals are not simply a counsel of amateurs; they are a challenge to the professionals.

Planning a Programme

This paper as a whole consists of an account of the resources, in terms of personnel, time and equipment, which Oliver needs if he is to make significant progress towards independence. But such resources in themselves are of limited use unless they are part of a co-ordinated strategy, an integrated 'package' in which the aims are clear and the goals precise. It is therefore essential that the Schools Psychological Service construct a programme of precision-teaching for each core area of the curriculum, including detailed task-analysis, the design of appropriate diagnostic probes, the setting of realistic goals within a continuum of genuine progress, and the establishment of daily monitoring procedures. There should be an ongoing reassessment of the programme at least once a term with the necessary adjustment of goals on the basis of this precise monitoring. Such a programme would involve close liaison and frequent consultation with teaching staff – and, indeed, their support, since monitoring would have to be conducted by them. Such a programme should ultimately cover all of the core areas discussed in this paper. But developing the means whereby Oliver can move as swiftly as possible towards the development of a channel of communication is a matter of the utmost urgency. Ian Andrews, an interfacing expert, has commented: “In view of the potential for Oliver's development, it would appear important to establish a proper procedure to monitor his progress. This would require a regular programme of measurement and assessment to record the nature and extent of his progress. Factors which would warrant such attention are:

1. Ranges of movement
2. Strength
3. Precise assessment of capabilities
4. Determination of perceptual sensitivities
5. Recording his communication capabilities.”

The development of Oliver's ability to communicate, then, should be the overriding aim of the co-ordinated strategy. But Oliver must have shared experiences to communicate. The role, therefore, of the “peripheral” curriculum should not be underestimated. Wherever possible, reinforcing links should be forged which undergird both the core and peripheral curriculum, so that the aptitudes developed in basic skills training sessions can be applied at a level meaningful to Oliver in an experiential setting. An example of this is the relationship between communication skills, reading, and practical activities. Blissymbol vocabulary acquired in training with the speech therapist (see CORE AREA 3 - STIMULATION: *Language*)

should be transferred to other contexts, with, for instance, Blissymbol stamps being applied to reading-books which cover topics within Oliver's home or school experience, or sheets of symbols generated by the 'Blissboard' computer-program via a printer (see CORE AREA 5 - COMMUNICATION: *Equipment and Materials*) being used as a basis for discussion or to label items in cookery, or providing the design-motives in art and craft.

The Use of Equipment

For many readers some of the high-technology equipment described later on in this paper may appear to be a series of strange and elaborate "gimmicks" which may appear to be more expensive and complicated than they are worth. The area of communication-aids and computer-assisted learning is a rapidly expanding one. While the particular products mentioned may not be the most appropriate as they are displaced by new items, we hold such equipment to be as essential to Oliver's education as writing materials and text-books to a 'normal' child. It is necessary to develop an even broader perspective. To reach an understanding of their fundamental importance we should appreciate our own dependence, as 'normal' adults, on tools to improve the quality of our life.

We may be able to use our hands, but the use of say, a hammer to extend these limits brings about a radical qualitative change to our environment. Even if we have the use of our legs, the ability to extend or replace their function by that ingenious device known as the "wheel" has not only facilitated mobility for the handicapped: it has had an incalculable effect on the quality of human civilisation. The extension of the ear and vocal chords by use of the telephone can overcome more than physical barriers. Perhaps the greatest breakthrough in the evolution of social organisation has been the extension of speech and memory by the invention of writing, and it is no wonder that so much emphasis is placed upon it in our education system. And yet even a century ago the mobilisation of society's resources towards the universal acquisition of this skill would have seemed impracticable. The importance of computer technology to the quality of our lives has yet to be quantified.

Applications purveyed to the mass market seem trivial - "space invaders" in more than one sense. For the handicapped, however, microcomputers have been described as "intellectual amplifiers" and "information prostheses". However we describe their function, to the victim of cerebral impairment,

the opportunities of brain extension offered by technology within the new discipline of Augmentative and Alternative Communication are crucial to their personal development.

CORE AREA 1 - BASIC SELF-HELP SKILLS

Feeding

Oliver can now swallow. He currently experiences some difficulty in mastication owing to some impairment in the lateral movement of his jaws. While some improvement may be expected as a result of facial massage and other exercises related to speech therapy, motivation is an important factor. It is important that Oliver should be allowed to express preference with regard to food, and that his diet should be as varied as possible. The texture of food should not be obscured by unnecessary mashing in order to speed up feeding. The best way to assist his digestion is by the use of sauces which stimulate and supplement salivation and by frequent drinks. Oliver should be allowed to eat extensively at will between meals in line with the eating habits of "normal" children of his age. Particular attention should be paid to oral hygiene, not only because of dental considerations, but also to avoid the de-sensitisation of his sense of taste.

Three considerations should be uppermost when planning a feeding programme:

1. Good food is an important element in Oliver's quality of life. Eating should be a pleasurable experience.
2. Improvement in the function of oral musculature brought about by eating will improve the quality and range of Oliver's vocalisation.

The quality of meals should compensate for the loss of appetite which is the inevitable result of limited physical activity, and avoid the debilitating weight loss and lethargy consequent upon malnourishment - an all too common phenomenon amongst institutionalised patients.

If Oliver is eating well and looks forward to meals, there is every reason to suppose that he will wish to assist feeding by signalling hunger and re-establishing relevant motor patterns. He has already demonstrated an ability to bring his hand and mouth together when hungry. Such actions will be encouraged if food offers a genuine, pleasurable reward for effort.

Toileting

Oliver has shown himself to be capable of exercising relatively advanced musculature control when there is sufficient reward incentive in terms of pleasure or enhanced self-esteem, and when he feels confident and secure about the context - in other words, 'at home'. Very complex mental processes are at work here, and we are faced with a 'grey area' between voluntary and involuntary movement. A great deal of patience and sensitivity is required on the part of the teacher or therapist in encouraging control, and effort should be directed at establishing a congenial environment for progress bearing in mind emotional, psychological and social factors as well as Oliver's own aspirations as a child.

Until recently Oliver was doubly incontinent. By consistently and painstakingly applying the principles outlined above over a period of several weeks his mother has succeeded in bringing about urinary continence. The same effort needs to be applied to bowel movement as Oliver achieves more regular habits of feeding and digestion. Given the more embarrassing nature of solid excrement and the more complicated mechanics of expulsion and disposal, considerable sensitivity needs to be exercised. Physical comfort during toileting is also of paramount importance if he is not to be "put off". Furthermore, if Oliver is not to be de-sensitised to the social aspects of toileting, and if his self-esteem is not to be undermined by the reactions of others, the accoutrements relating to this function should be removed efficiently to the appropriate place of storage or disposal, and inappropriate persons - such as strangers or even females familiar to Oliver - should not be involved in the logistics of toileting. Such considerations may seem trivial, but the impression left by the sight of a transparent bag of soiled napkins left in the social area of an institution visited by us has proved indelible. It spoke volumes about that institution's attitude to the inmates. As well as clear behavioural objectives, comfort and privacy should be paramount considerations if Oliver is to make progress. This entails a considerable amount of work for which there are few short cuts.

Dressing

Oliver can not actively assist in dressing. He should, however, be encouraged to help passively by the drawing of his attention to muscular tension which hinders the process. Dressing itself offers an opportunity to stretch muscles in a context which Oliver accepts as necessary, and a great deal of the tension precipitated by expectation of a "passive movement" session does not occur. For this reason we do not

wholeheartedly approve of labour-saving adapted garments unless they happen to be in tune with current fashion (such as track suits). It is essential that Oliver's clothes should be fashionable, be arranged in order to "hang" naturally, and any soiling should be swiftly and scrupulously removed. His appearance is fundamental to his self-esteem; his self-esteem is fundamental to his motivation; his motivation is fundamental to his progress.

Bathing

Oliver should be taught the importance of hygiene. As in the case of toileting, however, if we are to win Oliver's co-operation washing should be a pleasurable experience. Indeed, it is necessary for those assisting him to appreciate the positive opportunities offered by the necessary ablutions. The temperature of the water, hot or cold, applied in washing can be used as a means of stimulation or relaxation. Drying can provide a stimulating massage aiding circulation. Use of aromatic toiletries can provide Oliver with some pleasure and stimulate his sense of smell. (The use of an array of bottled aromas proved invaluable in reviving Oliver from his coma.) Bathing should not therefore be regarded as a chore to be rushed, but as an event to be savoured, and wherever possible should be concluded with an oil or lotion massage. Similarly, bathing in a pool may be preceded or concluded with a sauna which will relax him and enable him to derive the maximum benefit from hydrotherapy.

Choice of bathing equipment needs to be given careful consideration. The shower can provide occasional stimulation; it should not be employed as a convenient expedient in a mere 'hosing-down'. A bath is to be preferred since it provides opportunities for leisurely play and variation of posture. In this respect the Parker Bath is useful since it reduces the risks associated with a very dependent patient in water, thus facilitating play. A "jacuzzi" or whirlpool-bath has obvious benefits for the paralysed child. A device marketed under the brand-name of "Relaxabubble" extends a similar effect into an ordinary bath.

Once again, it is necessary to emphasise that what for a 'normal' person may be self-indulgent luxury may be for the sensorily-deprived a means of providing social interaction and that shared experience from which the desire to communicate springs. This is the peripheral curriculum in the broadest sense.

CORE AREA 2 - PHYSIOTHERAPY

Gross Body Movements

While most of Oliver's movements (excepting, perhaps, those in the right hand) are not entirely voluntary, neither are they always entirely involuntary. He can undertake major movement when he wishes to draw attention to himself. He can control equipment such as a tape-recorder or slide-projector by use of a micro-switch when the end-result is interesting to him or adds to his peer-group status. Emotional, psychological and social factors have a considerable influence on his performance. (See CORE AREA 1 - BASIC SELF-HELP SKILLS: *Toileting*).

So-called "spasm" - a term which we consider to be totally misleading - should not be regarded simply as a neuro-physical problem within a body-mechanism which is entirely out of control. The phenomenon appears in certain identifiable contexts as the result of Oliver's emotional condition. For example, when he is hungry his unease leads to tension in the abdominal muscles causing him to "flop" forwards-so-called 'adductive spasm'. Similarly, when he is anxious about an impending event his right leg may straighten and his foot turn inwards. Both pathological reactions are undoubtedly exacerbated by his inability to communicate his anxieties effectively. Use of muscle-relaxant drugs such as Baclofen or corrective implements such as callipers should be seen in perspective as convenient short-cuts to control of the body-mechanism by external means, and a supplement to, rather than substitution for, daily physiotherapy. A normal growing child not only engages in a great deal of physical activity, he develops skills by monitoring his own performance. This monitoring is sometimes explicit in children's games, such as skipping or hopscotch or 'snobs', or in popular sports. Oliver's inability to participate in such activities, and the effect of this on his growing physique, must be compensated for by an ambitious and very labour-intensive programme of physiotherapy.

But the challenge to the health service consists not only in providing adequate staffing, but also in staff taking account of Oliver's advanced cognition and sentience. He is capable of monitoring what is happening to his body and of searching for internal strategies of exercising control. He must help to find solutions from within himself, but education can assist him. This involves both teachers and therapists in

- (a) providing verbal (or other available) feedback in the form of observations to Oliver about what is happening to his body;
- (b) undertaking an analysis of the context in which such changes occur;
- (c) suggesting strategies for the remediation of such changes by Oliver himself.

Simple examples are as follows:

Feedback: "Oliver, you're getting all tense. You're sticking your leg out." *Analysis:* "You always do that when you're worried about something. Is it because you're going to the dentist this afternoon?"

Remediation: "For goodness sake relax. It's only for a check-up. Getting tense will only make you feel worse".

This is a very simple example of the dialogue which would accompany physiotherapy (in this case, gentle manipulation of the affected leg) in the context of a continuous process of holistic therapy or curative education which treats Oliver as a complete psycho-somatic entity.

The insights inherent in this approach can be refined into more precise educational strategies: *visual feedback* can be provided by video and mirrors; *aural feedback* can be provided by attaching mercury switches which activate buzzers; *tactile feedback* can be provided by vibrators. The use of EMG signals in providing feedback should not be discounted. *Analysis* can take the form of one-to-one discussion of the day's programme or discussion at potentially stressful periods such as before mealtimes, visits, or physiotherapy sessions. *Auto-remediation* can be facilitated by changing Oliver's perspective, either physically by altering his posture or mentally by humour.

These approaches may overlap. The educative part, for example, of a hydrotherapy session might run as follows: "Can you see, Oliver, how when we move your head backwards and forwards your body goes up and down? (Demonstrate). You're not floating very well now because you're all tense. Is it because the water isn't very warm? (Elicit answer). Is it because you think I'm going to let you sink? (Elicit answer). I'm going to pull you through the water now. You won't get a good ride if you don't relax."

Such an exercise is educative as well as therapeutic: it is exercising Oliver's mind as well as his body.

Clearly, physiotherapy or hydrotherapy which simply manipulates the patient without adequate explanation can have counter-therapeutic effects by unconsciously emphasising his helplessness, and by rendering the patient suspicious, anxious, and therefore physically tense. A valid approach needs a frequent session of significant duration. Whether conducted by a teacher or by a physiotherapist we would envisage a daily session of an hour's duration, with the therapist bearing in mind that language and mental interaction is a fundamental part of the process.

Sitting and Standing

Oliver's position needs to be changed as often as is conveniently possible between seated, prone and supine. Since he is growing at a normal rate we need to take maximum advantage of his current manageability. In view of his scoliotic condition perpetual vigilance needs to be maintained to keep his pelvis and torso correctly aligned, whatever his overall position. While moulded seats and vacuum-cushions can maintain an acceptable posture, a chair needs to be supplied which is mildly corrective if use of a restrictive body-jacket is to be forestalled.

Such a seating arrangement is particularly important for when Oliver is working. He needs to be placed in a position which is clearly workmanlike, and which maintains his posture steady while he concentrates on the task in hand. If his overall posture is constant, it leaves the way open for fine adjustment in the limbs he is utilising. Thus, for example, his head needs to be steadied in order to help him fine-tune his gaze and apply consistent pressure to a chin-switch. Similarly, since other muscles may react to a neural message sent by Oliver to his hands, switches in this area need to be very carefully placed; a constant posture will assist careful experimentation. Needless to say, any chair needs a detachable and adjustable tray as a working surface.

A chair therefore needs to be provided with thoracic and pelvic pads and a fully-adjustable head-support. Thus Oliver's scoliosis could be controlled by the use of bi-lateral pelvic pads, with the extension of the pad upwards on the side of the convex lumbar spine, and using just one thoracic pad on the side of the convex thorax. This would help to straighten the spine and improve stability of the trunk which in turn will improve the sitting posture. Head supports need to be provided which are fully adjustable for height and width, and

a nape-of-neck support needs to be incorporated. A tilting mechanism would add flexibility, facilitating adjustment to the task in hand or countering the effects on Oliver's posture of gravity - while keeping his corrected posture constant.

All the necessary modifications described above can be supplied by The Spastics Society for application to the Avon range of wheelchairs. Corrective pressure to Oliver's feet and lower-limb joints can only be effectively applied by maintaining him in a standing position. The use of a prone-table has the added advantages of improving Oliver's body-consciousness, developing his head control, and may open possibilities - perhaps through the use of slings - in the utilisation of movement from the shoulder or elbow. It will improve his blood-circulation. Finally, a change of physical perspective will add depth to his perception of his everyday environment.

CORE AREA 3 - STIMULATION

Language

Even within the context of a Special School children who cannot talk represent a special minority. Their handicap strikes at the very roots of the educational process. Clearly, non-verbal children are vulnerable to bad educational practice since they do not have the ability to make obvious protest against an unstimulating environment. Furthermore, since both formal and informal assessments of intelligence tend to be based on speech, it is almost automatically concluded - often by people who should know better - that such children have poor educational potential.

In the normal classroom situation non-vocal children may be neglected by the hard-pressed teacher. There may, therefore, be a case for limited withdrawal of such pupils. Such a group, however, should not be a negative way of dealing with an educational "problem" - the classic "sink" group. Stimulation provided by talking peers should only be temporarily removed in exchange for a genuine intensive language-enrichment programme in which a teacher's full creativity is made available to a smaller group of pupils. Oliver's speech therapist has initiated the use of Blissymbols in her weekly session. If Blissymbols are to serve as his main expressive medium for the foreseeable future the use of the system must be carried over into the school curriculum and into social contexts. A withdrawal-group provides the opportunity for an intensive application of the system through specially-adapted materials and equipment. Games, in particular, are an excellent way of

extending vocabulary and encouraging social interaction. A special classroom-area reserved for the group should be decorated with stimulus-material using Blissymbols. Withdrawal sessions may provide a workshop in which the system can be applied to subjects taught in 'normal' class time. Both the Local Authority and the Speech Therapy Department should face the challenge by providing special materials and preparation-time for the teacher involved. If a Bliss-trained teacher is not available then daily speech therapy must be provided.

Preparation of Blissymbolics materials is extremely time-consuming. Commercially-produced materials such as stamps and flashcards can lighten the load considerably, as can print-outs from Blissymbolics computer-software. For example. Gait word-building blends can be adapted by sticking Blissymbol stamps onto the plain half of the tablets. These then have the dual function of providing clues in the word-completion exercise and of encouraging symbol-acquisition through the matching of picture and symbol. In Oliver's case, while it requires manipulation by the teacher presenting him with alternatives and eliciting a Yes/No response, it develops his residual knowledge of phonics while encouraging use of the "new" semantography. In the same way, appropriate books (with simple text but with pictures and themes at the right age-level) can be dismembered and reconstituted as "zig-zag" books for Oliver to browse without having to turn pages, with Blissymbol stamps applied to the illustrations.

Talking machines can be a fertile source of language stimulation. Unfortunately, machines such as Texas Instruments "Touch and Tell" or "Vocaid" or the Bell and Howell 'Language Master' are not usable without a fairly advanced degree of manipulatory skill. It may be that the newly-developed "Convaid", which is similar to "Vocaid" but with a greater range, may be usable at some point in the future since it has the capacity to be adapted to a double-switch input controlling scanning LED's. Using any of these as a teacher-controlled resource at the present moment in time would, of course, be under-use of expensive equipment. Oliver can, however, control a tape-recorder. He could, therefore, make use of a Ricoh "Synchrofax" machine. This displays a hand-written overlay. The reverse side of the sheet allows for magnetic recording of up to four minutes of spoken material. Otherwise, the controls are not unlike those of a cassette tape-recorder. In Oliver's case, this machine would effect a happy compromise between pupil and teacher-control. Blissymbols could be drawn onto the overlay. The teacher's voice could record the meanings. Oliver himself could control the rate of play.

Talking machines are particularly appropriate to Oliver's needs in view of his excellent hearing and aural comprehension. In view of his vision problems, however, language development material which offers a strong visual stimulus is at a premium. "Pop-up" books, while having plenty of visual impact, do not necessarily draw Oliver's attention to text. In this respect the slide-set 'Say It with Symbols', produced jointly by the Blissymbolics Communication Foundation and the Film Board of Canada (1976) is ideal. It has the added advantage of tackling the problem of a vocabulary extension strategy based on other than phonic considerations (as is the case with most standard vocabulary lists.) A sequence of graded vocabulary is incorporated within the total scheme, while component slide-sets may be used frame by frame or in a narrative format.

Sensory Stimulation

The importance of stimulation in motivating a brain injured child towards progress first became apparent when Oliver was still comatose and items such as a tape-recorder with earphones and an array of scent bottles became important tools in encouraging Oliver's increasing grasp of the "real" world. Indeed, the use of stereophonic headphones with an audio or video-tape recorder, thereby concentrating the aural stimulus, remains a source of considerable pleasure to Oliver - particularly in view of the fact that these media are his chief substitute for reading, and should be regarded positively as such. Nor should the role of music therapy with a qualified teacher be discounted. In our opinion, it is an essential component of any programme of stimulation.

It should be understood, however, that pleasure is not the main object of stimulation. Understanding and control of the real world is the main goal. This can be analysed into two aims:

1. To provide Oliver with well-defined and pleasurable sensory feedback in response to his attempts to exercise control over his external world, and to order the stimuli which the world of the senses offers to him in such a way as to offer possibilities of control.
2. To allow Oliver, by means that are reassuring rather than threatening, to develop an awareness, through sensory feedback, of the spatial extent and potential capability of his own body, and thereby facilitate creative ordering of his internal world.

With regard to the first aim, Ian Andrews proposed the following: "The first essential is to try to establish the means whereby Oliver can exert control over something. That something must initially be a dominant response which makes it blatantly apparent to Oliver that he has done it. Similarly it must be of such a nature that Oliver is able to control it by himself. Further, the nature of the system must be such that Oliver can be left with the equipment so that he can practise as much and whenever he chooses. Reward devices which would be best at this first stage are:-

1. A vibrator unit.
2. A sound and light unit.
3. A large train set on a circular track.

These, taken in this order, represent a gradual development of sensitivity to stimuli. The *vibration* can be applied either as a small module inserted in a jumper sleeve, pushed into a supporting strap, or similar. Further the vibrator module can be fitted to an inflatable cushion and can then be used as a vibrating cushion on which Oliver can either be lain or it can be used as a cushion on his chair. The vibration sensation, when it is used as a cushion, can be supplied either to the seat or to the back section. As a reward sensation, it is directly effecting his immediate awareness.

A *sound and light* unit would provide a strong reward which would be located near to Oliver but would be perceived by his eyes and ears rather than by direct body contact. It takes his attention to a larger distance from his inner self. The sound and light source can be moved further from his person so that the extent of his perceptive abilities can be ascertained and probably expanded.

The *train* takes this one stage further and makes the source of the reward of longer term interest. There can be a sense of greater control when driving a train than merely controlling a light. Another aspect which arises naturally with the use of a train is that it begins to present an eye following task with the potential for obvious visuo-motor challenge - that is, to stop the train at a particular position etc."

Mr. Andrews recommends an interface device to add versatility similar to the one already developed by Manchester S.E.M.E.R.C. (see CORE AREA 4 - PLAY: A Toy Control System).

The *control unit* which acts as an interface between the elbow switch (and the others) and the reward devices should be as

versatile as possible. It is most economical to make maximum use of anything which needs to be in a metal case and requires a power supply. It is therefore appropriate to conceive that this unit will perform the following functions: (1) power the sound-light unit (2) provide whatever facilities prove necessary to control the train (3) give the facilities for the elbow switch. (This allows devices to be switched if the elbow is bent or straightened by various amounts. Initially only a tiny movement can be asked before it switches and this can be developed as needed.) (4) give control of many devices for selection from a single or multiple switch input.

Most of the functions of this unit can be done by a computer system. Switches are discussed in greater detail elsewhere (CORE AREA 4 -PLAY: *Switches*). With regard to the second broad aim outlined above (Page 20). Mr. Andrews offers the following comments and observations: "During my visit we allowed Oliver to experience the sensation from a small battery-powered vibrator unit. This provoked a distinct interest . . . As a general response it is a very effective way to make apparent to children that something is happening." His speculations regarding the application of such a device provide an interesting complement to the discussion of strategies for auto-remediation in CORE AREA 2 - PHYSIOTHERAPY: *Gross Body-Movements*. ". . . we have just discovered that by using a more sophisticated electrical drive system, we can achieve a wide range of frequency control and we can now employ such a system to excite particular parts of the arm. Now it is known that muscle systems grow under such conditions and it appears therefore that there may be significant therapeutic benefit from such a vibration device. The use of small electrical nerve stimulators is becoming common in many kinds of situations involving pain control. The potential for use of such devices for making children aware of the nerve systems in their limbs is something we are beginning to explore as it may well complement a vibration therapy system. The two techniques may provide a comprehensive approach to the stimulation and development of limb behaviour."

Clearly, such observations take us to the frontiers of orthodox therapy, and for that reason alone are likely to meet with a great deal of opposition. These proposals are a challenge to the creativity and openness of therapists currently treating Oliver.

Finally, Oliver's vision needs to be mentioned, although the repercussions of his problems in this area *vis-a-vis* the use of a communication aid are discussed elsewhere (CORE AREA 5 - COMMUNICATION: *Problems of Communication; Communication Skills*). In order to develop the optimum use of his vision Oliver needs a training device which mimics the operations of a visual scanning display but which allows extreme simplification of the information to be processed. A matrix of coloured lights reinforced by a note scale would be ideal, particularly if it allowed meaningful elements (symbols in terms of sight and spoken words in terms of sound) to be incorporated within the basic routine as Oliver's skill progressed. To date, we have not seen any such apparatus. In view of this lamentable fact developmental work may have to be commissioned on the basis of readily available technology.

CORE AREA 4 -PLAY

A Toy Control System

Toys can provide the reward incentive necessary to encourage Oliver to develop the skills essential to operating a communication device. In general, when Oliver can achieve so little for himself, enabling him to play is crucial to his motivation towards exercising some degree of control over his world. Oliver's present physical ability to barely operate one switch at a time does not present a great deal of scope. (Although there is every reason to maintain expectation of natural improvement, he must not be placed in limbo. Oliver, as a person, has needs which must be faced now.) Furthermore, his current inability to cope with rigorous time constraints in processing and referring visual information excludes for the moment any use of commercially available computer games. Both difficulties can be overcome, but there are initial problems.

Obviously, the only toys which Oliver can control are those requiring minimal physical movement and co-ordination: battery-operated devices with remote switches. Since a single switch can generally only initiate a single operation such toys are unlikely to sustain the interest of a child at Oliver's level of cognitive ability. The quality of the reward, however, is not the only factor involved. The appeal of the toy is also related to the amount of effort needed to operate it. If the task of operation is too simple, Oliver will quickly become bored with the toy. If, on the other hand, the amount of effort required to operate the toy outweighs the quality of the reward there will be no incentive to perform the task. Thus toys are needed which offer

interesting effects, and the effort needed to operate them needs to be finely graded according to Oliver's developing ability.

The rudiments of such a system were hinted at in the last section (CORE AREA 3 - STIMULATION: *Sensory Stimulation*), but Manchester S.E.M.E.R.C.'s Micro-Active Toy Control system offers the best available opportunity of solving these problems.

To operate the system to its fullest advantage, a wide range of switches need to be developed which terminate in a quarter-inch jack plug. (See next section for switches appropriate to Oliver.) These would then be used to operate any of a wide range of toys, all controlled from a jack socket. The toys may include battery-operated cars, electronic sirens and music boxes, rotating beacons, cassette tape machines, disco lights and so on. With the aid of the Micro Active interface it is possible to interpose a microcomputer between the user's switch and his electrical toy. The interface is constructed with jack-sockets for switch and toy. One program, TOY REPEAT, prompts the teacher to key in the number of switch operations necessary to turn the toy on. Another program, TOY HOLD, controls the amount of time needed to press down a continuous mode switch in order to achieve the reward. In this way, a wide variety of input and stimulus conditions can be combined to present to Oliver an appropriate and rewarding task. The microcomputer element can also provide the teacher with an accurate and detailed record of his performance on the V.D.U. or printer. Such a system (now available through commercial suppliers for B.B.C. or Spectrum) has a built-in task analysis which enables play to be used purposefully towards graded skill acquisition in the context of a programme of precision teaching.

Switches

Switches are of paramount importance to Oliver: for the foreseeable future they will provide him with his only means of active control of his environment and exploration of the world. We have seen the importance of stimulation, but the scope of his development is severely limited as long as he is only a passive recipient of stimuli. Choice is fundamental to his self-esteem, motivation and understanding. This is why it is imperative that his existing ability to express preference through his Yes/No code should be used to the maximum, but this can only take him so far.

For this reason, it is essential to provide Oliver with a *range* of switches. To claim that it is necessary to wait until he has proved competence in a particular operation before a switch

can be provided is an absurd proposition. No educationalist would dream of depriving, for example, a "normal" child access to books before it had proved its competence to read. There is no doubt that Oliver can be trained to develop competencies which currently exist only as ill-defined potential. He must be placed in situations which are challenging to him, and which make full use of his undoubted ability to understand the challenge, assess for himself his own degree of competence, and develop, either consciously or unconsciously, strategies to overcome his difficulties. The sense of achievement which comes from mastery of the environment, no matter how limited, is of the essence of education. Any child needs an environment in which there is scope for experimentation in tasks and skills which may - or may not - prove to be self-fulfilling.

For this reason, a range of switches must be made available - linked to appropriate feedback devices - in an experimental "workshop" situation. Before we discuss, however, the lines along which such a workshop might develop, it is necessary to say something about the interfacing process. Despite the fact that interfacing - the selection and installation of a device which allows a person to control an electronic aid - can determine the success or failure of the use of an aid, there seems to be an alarming paucity of reliable advice available. D.H.S.S. assessments tend to be cursory and parsimonious. O.T.'s tend to be "computer-phobic". Teachers, faced with new developments, are often obliged to improvise with whatever is available. Commercial suppliers - if you know where to find them - lack objectivity. Doctors and consultants can be alarmingly ignorant. Statutory services in this country have a great deal of ground to make up.

Assessment packages have been developed in Canada and the U.S.A. A package being developed at the Ontario Crippled Children's Centre isolates four factors:

1. Residual controlled movement;
2. The choice of (body) site;
3. The choice of interface;
4. The method of placement.

At the Massachusetts Institute of Technology client profiles are based on factors of Reach, Force, Speed and Accuracy. Geb Verburg ("Hooking Up' to the Computer" in *Communicating Together* Blissymbolics Communication Institute, Vol. 1, No. 3, Summer 1983) identifies some of the questions which we are on the brink of facing with Oliver:

- “ – Should one, two, three or more switches be used?
- What are reliable rules of thumb or decision criteria concerning when to use a special interface system?
- When should an interface system be changed?
- How does one anticipate and promote physical and mental development through the choice of an interface system?
- How does one optimally take account of a person's preferences (and a youngster's change in preference when the charm of a special input and/or output system turns into a stigma)?”

Clearly, Oliver's teacher, therapists and care-givers are faced with a daunting task. The sooner it is undertaken the better.

Because of social considerations it would seem wise to concentrate on areas which might be used by a 'normal' person to operate switches, such as the hands. This may not prove viable, and less usual areas of Oliver's physique should be considered. Even if problems prove intractable here, the scope for development is not closed. In the article mentioned above, Verburg points to other possibilities: “Where none of these overt means of control are applicable, it is possible to reach beneath the skin's surface and draw upon the body's internal signal system. An interface exists that reads electromyographical (EMG) signals, ie. signals that control the muscles, and research is being conducted that uses the electrical activity of the brain to determine what a person is looking at.”

CORE AREA 5 – COMMUNICATION

Problems of Communication

Since Oliver (at the time of writing) cannot indicate effectively with his fist any communication system must be dependent either on eye pointing, or on a mechanism operated by a micro-switch. Oliver has also begun to use a head wand and there is every reason to expect that this capability can be refined with practice. Because of this developing situation any non-mechanical communication aid ideally needs to be multi-purpose in design, capable of being used for eye pointing, head pointing, and as a teacher controlled aid.

Before we discuss any such aid in detail, however, it is necessary to discuss some of the problems which need to be overcome.

Oliver is just beginning to develop some competence with a thumb switch in his right hand, but at this early stage (as discussed in the previous section) a range of switches needs to be provided with appropriate feedback devices which would facilitate a programme of precision teaching. Since, however, any mechanical communication device involves operating a switch in response to a visual stimulus, Oliver's hand-eye co-ordination needs also to be developed.

He is experiencing certain difficulties with his vision. According to his own testimony he cannot see with his right eye, although it is difficult to interpret this. He also appears to experience some difficulty in tracking which may be the result of a slowness in focussing on the temporarily static stimulus. This would correspond to the slowness of movement in other areas. This, of course, may improve as Oliver establishes alternative pathways of voluntary control. On the other hand the problem may be more fundamental than a defect in the neuro-muscular focussing mechanism. He may be suffering from a-centric tunnel vision. This might enable him to see objects clearly *only* when they are moving. (People with normal vision can experience the effect of this by observing a stimulus out of the 'corner' of their eye.)

The practical outcome of the defect is that Oliver appears to require a more than normal time in reading a sentence and may "lose" a moving L.E.D. on a visual scanning display system such as a POSSUM Communicator 16. Since these difficulties hinder his educational progress it is important that we have as much precise information as possible at our disposal. Unfortunately, further information on this problem is not forthcoming. We have found that medical consultants are not above the most primitive prejudices regarding the victims of cerebral damage and with disappointing consistency have automatically assumed that Oliver is incapable of providing reliable information about his own problems. It is therefore a matter of lay speculation as to whether the source of the problem is within the eye-muscles, optic nerve or visual cortex.

Continuing our speculations, it would appear that Oliver's major problem is with tracking. He is capable of seeing any static object in great detail - a die, for example. He is also capable of seeing movement: as was witnessed by his amusement whenever the Communicator 16 was switched to maximum scan rate - which is very fast. He is also capable of interpreting a complex moving stimulus, such as film or television. Some months ago auditory reinforcement was undoubtedly a factor in his comprehension, but now it is obvious that he can understand visual humour. For example it was quite apparent recently that he was deriving great

pleasure from the T.V. screening of a silent film starring Harold Lloyd. Oliver's "problem", then, may reside in his impaired ability to process the information offered by a stimulus which changes its location and is alternatively static and moving.

Oliver needs to be able not only to visually track a "stop-go" stimulus but also to control its movement by means of a switch. Here his problems may be compounded by impairment of the pathways which undertake the referral of information towards correlation. In other words, brain damage may have affected his ability to relate two tasks simultaneously. Thus, presented with the task of both operating a switch and of processing complex visual information, he is unable to do both effectively. It is quite possible, of course, that when Oliver self-consciously attempts to perform such a task he tries to use 'old' now-damaged circuitry which is ineffective. Again, there is every reason to suppose that these problems may be slowly overcome with training. Motivation is clearly a factor in Oliver's progress. Feedback must be unambiguous, entertaining, but with sufficient subtlety to hold his attention. Recently, for example, Oliver appeared to lose interest in using his thumb, particularly when faced with his difficulties in using the Communicator 16. When a new application was found for the device as a die, with locations being selected randomly with the device on the maximum, uncontrollable, scan-rate, Oliver "re-discovered" this particularly movement.

This is Oliver's problem *vis-a-vis* communication in a nutshell. On the one hand, we have a child whose ability to process sensory information and perform simple manipulatory tasks is at pre-school level. On the other hand, we have a child whose grasp of meaning and whose cognition and associative functions are normal. If Oliver's ability to communicate is to develop, these disparate capabilities must be made to converge in a system which is capable of increasing levels of sophistication.

Eye Pointing

In the first instance, an eye pointing programme using Blissymbols should be developed. Once again, we must emphasise the need for any techniques acquired by Oliver to be extended beyond the speech therapy session into the school curriculum. And as in the case of creative play, precision teaching based on realistic task analysis and thorough monitoring must be pursued if the all too frequent drift into a hand to mouth approach is to be avoided.

The programme developed by P. J. Conner at Como School, St. Paul, Minnesota, U.S.A. (in H. Silverman, S. McNaughton, B. Lates: *Handbook of Blissymbolics*, Blissymbolics Communication Institute, Toronto, Canada. 1978), suitably adapted, may form the basis of such an approach, Conner's own summary is as follows:-

"1. Establish two gross eye-pointing positions (left and right of the vertical midline) which allow for a reliable indication of choice.

2. Establish colour associations (eg. red and green) with the two positions learned.

3. Transfer the two colour-coded eye-pointing responses from the horizontal to the vertical plane.

4. Establish 10 colour-coded eye-pointing positions on a perspex sheet (vertical plane).

5. Develop a 10 symbol, one colour-code eye-pointing communication board.

6. Develop a 10 symbol, two colour-code eye-pointing communication board.

7. Establish 'yes' and 'no' response positions on communication board.

8. Transfer use of two colour-code eye-pointing response to 100 symbol board.

9. Establish 10 number-coded eye-pointing positions on a perspex sheet (vertical plane).

10. Train the child to retain and eye-point to sequences of two or three numbers.

11. Transfer use of number-coded eye-pointing response to 200 symbol-board and/or 400 symbol-board (with symbols numbered consecutively, starting from upper left corner to lower right corner)."

Step 7 in Oliver's case is not essential since he can efficiently indicate "yes" and "no" by a well-established code. Indeed, since teachers and therapists are not always scrupulous in ensuring that Oliver has understood a particular task (partly because of doubts, based exclusively on prejudice, about his level of comprehension), utmost care should be taken to check

via the code that Oliver has understood the task before proceeding.

Equipment in the form of an E.T.R.A.N. frame needs to be provided for this mode of communication. Any unit should involve

- (a) No more than two eye-points;
- (b) A large format to facilitate more definite interpretation of eye-movements;
- (c) Interchangeable symbol units to facilitate careful vocabulary extension within the same system;
- (d) A device for developing syntax;
- (e) A vocabulary-extension strategy. Such a unit could be based on a free-standing triptych with "windows", enabling the teacher or therapist to more readily identify Oliver's eye points. A concave shape would enable the same system to be used with a head-wand. Oliver's use of a head-wand needs to be developed since it requires less concentration on the part of the message recipient than eye pointing. Also, a communication board used with a head wand can be portable in the form of a wheelchair tray. Such a tray - raised, tilted, and with a cut-out for Oliver's torso - needs to be provided.

The problem with both units described above is that of providing for the interchangeability of display items. Systems could be devised which use transparent overlays in acetate, acrylic or P.V.C., or magnetism, or velcro strips. The display items themselves should not present a problem. The time-consuming activity of drawing symbols with a template can be largely by-passed - except in the case of "personalised" symbols (eg. "Lottie" instead of "dog") - by the provision of several sets of commercially printed Blissymbol flashcards and stamps (supplied by *Living and Learning*, Duke Street, Wisbech, Cambs.). Such materials can also be given a non-utilitarian application to displays, books and even objects. (See CORE AREA 3 - STIMULATION: *Language*.)

For general teaching a magnetic display board ("Magiboard" - desk-top model) needs to be provided. Teaching can be conducted by drawing directly onto the board with a felt-tip pen or by applying symbols or letters pasted onto magnetic rubber flaps. (Materials prepared for a "Magiboard" can also be used with a magnetic pointer board - see *Equipment and*

Materials.) Any *ad hoc* display could then be worked on by Oliver using a head wand or eye pointing.

Communication Skills

Skills developed through procedures described in CORE AREA 4 - PLAY need to be applied to a communication system using switches. Despite his visual and motor difficulties, Oliver needs to be trained in the use of a visual scanning device which preferably uses aural reinforcement, and which can be used in a non-automatic mode. A suitable piece of equipment may have to be commissioned. In the meantime a device using six or ten locations with a bleep facility is manufactured by Geoffrey King Enterprises (54 Chenton Road, Winchester, Hampshire). Equipment and procedures described in previous sections should lead to progress in this area.

Equipment and Materials

The communication device which can perhaps be put to optimal use at this stage of Oliver's development is a mechano-electrical pointer board. Two models are commonly available. The "Telemachus" model, while it can be used horizontally to indicate objects, needs to be disassembled in order to display items behind an acrylic frontage panel. The "Q.E.D." model is magnetic, thus facilitating use of materials prepared for a desktop "Magiboard". The portable model also has a speed control knob varying the rotation of the pointer between 2.5 and 5 revolutions per minute; thus Oliver's mastery of this device could be extended. It is also possible to insert indicator lights at various locations around the circumference, reinforcing the visual stimulus.

In view of Oliver's vision difficulties - perhaps situated, as previously mentioned, in his cerebral sensory-motor referral centres - he will probably need to be coaxed towards hand-eye correlation and co-ordination. He should therefore be briefed on the content of any items placed on the pointer board, perhaps by means of the "Magiboard", before they are placed in position. Also, initially, he will need auditory feedback as the pointer passes round the board. Since the device does not provide this electronically, it would have to be provided verbally by the teacher. As usual, close monitoring needs to be maintained in order to gradually increase the complexity of the task - including the gradual withdrawal of preliminary briefing and auditory feedback.

Oliver's motor difficulties currently result in problems in releasing a switch, and it may be that the one press/one

location movement device described under *Communication Skills* may offer more scope for development in the early stages. It is, however, imperative that some effort be made to develop Oliver's visual tracking ability since most "higher" communication aids for the disabled - most commonly marketed by POSSUM - rely on this ability. In view of the educational need, the visually simpler scanning mechanism of the pointer board may be the best introduction to an automatic continuous mode.

Once these skills have been acquired we may then think in terms of a patient-operated computerised communication aid accessed via a visual scanning display. There are several such systems on the market, either consisting of a software package enabling a commonly available microcomputer such as the Apple II to be used in this way by means of a cursor-accessed matrix on the V.D.U., or incorporating specialised hardware. An example of the latter is the S.P.O.C. (Speech Output from Computer) package recently developed by Techneg Clwyd Ltd. Incorporating a speech synthesiser, this hardware and software package based on the B.B.C. micro is accessed through a visual display unit which scans 160 locations. These can then be de-coded by the computer to correspond to the Bliss core vocabulary chart. C.E.A.D. (Communication and Environment Aid for the Disabled), also based on the B.B.C., enables the user to manipulate text on the monitor via a single switch input, and incorporates an environmental control system. (See CORE AREA 6 - ENVIRONMENTAL CONTROL.) A fair range of programmes have been written for the B.B.C. for use with a single switch input. Mr. J. M. Leonard of Lickfield, for example, has designed a typing programme ("Autotype") and some games ("Noughts & Crosses", "Line of Four", "Draughts" and "Fox and Geese") for use in this way. Although a computer can be used at this stage to develop Oliver's basic skills - through use, for example, of the Micro-Active Toy Control Interface - he is clearly some distance away from using such equipment as a direct communication aid. The problems which must be faced are discussed under *Intermediary Systems*. In the interim period, however, there are considerable advantages - not the least being Oliver's habituation to this kind of technology - in using a computer system controlled by the teacher or therapist. When a computer is used in this way, however, it should be observed as a general principle that only software which Oliver may be able to handle at some future stage of development should be used.

A good example of this is the Blissymbolics software written for the Apple II system. "Talking Blissapple", developed by the Trace Research and Development Centre, U.S.A., enables the teacher to build syntax on a monitor from a chart-based user-vocabulary. Each symbol in the lexicon is numbered or may be ascribed a number, and there is a system for accessing numbers displayed on the screen by means of a single switch controlled cursor. As each symbol is selected Oliver could receive auditory reinforcement via the speech synthesiser and the printer could supply a permanent record of the ground covered. The suite of programs - "Bliss Library", "Blissboard2" and "Bliss Drills" - developed by the Minnesota Educational Computing Consortium, U.S.A., is parallel to "Talking Blissapple", but has a refinement which is applicable to Oliver's needs at his present stage of development. As would be expected from software developed from trials within special schools, "Bliss Drills" is an educational programme rather than a straightforward communication programme. Users are invited to match one of a short series of randomly displayed symbols with the "permanently" displayed symbol. Both stimulus and distractors are from a thematic group such as 'family', so that meaning related groups are learned. The flash rate of the match sequence can be regulated from one to ten seconds - while the programme is running, if necessary, by the use of a paddle. Correct matching is rewarded by a "smiley face"; incorrect matching by a "sad face". Needless to say, the matching can be done by a single switch. Such a programme answers precisely to Oliver's needs not only by extending Bliss vocabulary but by encouraging simple visual acuity and developing fluency.

Intermediate Systems

One of the most urgent problems facing Oliver and children like him is the leap in expectations of the patient/pupil from a simple device such as the pointer board to a computer based communication aid. Unfortunately, most purveyors of computer-systems for the multiply handicapped skirt around this problem.

There are undoubtedly some developments in academic institutions which may never be marketed commercially. South Glamorgan College of H.E., for example, has done some work on visual stimuli. These include a dedicated 8 x 8 array of lights than can be programmed, and programs for shape and colour recognition. Further information is not readily available at this stage, and it is hoped that such initiatives as the organisation of a database at the Newcastle Polytechnic Handicapped Persons' Research Unit will make such expertise more readily available. More readily accessible centres, such as

Manchester S.E.M.E.R.C. or Walsall E.D.C., or the Midlands Centre for Neurosurgery and Neurological Research, might be called upon to provide information or expertise which might help Oliver.

A few resources are available commercially. Geoffrey King sells a suite of programmes for the Sinclair Spectrum and ZX-81, one of which, "Doorman", is entirely appropriate to Oliver. A "man" moves very slowly across the screen towards a "door". When he arrives the user is expected to press his switch. Correct timing conjures a "smiley face". Success automatically increases the rate of approach, failure automatically decreases the rate. A record of performance appears on the screen. Besides providing Oliver with a task which is entertaining and which he can actually perform, it is an important diagnostic tool providing valuable information towards the use of a visual scanning system. Elfin Systems have also developed software which allows large format symbols to be scanned towards the control of linked appliances.

It is an area which developers are gradually becoming aware of: namely, the educational potential within a computer system to train up the user to increasing levels of complexity. This realisation informs Ian Andrews' description of his own prototype system, the "QuCee": "The ultimate aid for Oliver is undoubtedly some form of computer since it would give him the means to produce a record for communication to others. As yet such a facility is far beyond his compass. What is really required is some system which operates on the basis of reward for simplest action and which can expand in the tiniest of stages upwards by introducing choices and tasks of ever growing complexity. Such a system is now in prototype stage in our laboratory. It is being developed for children with just the requirement of Oliver. Such a system gives the facility of having a computer which is tailored precisely to the exact needs of the child. It can grow with the child from their starting capability of nothing right up to the stage from which they could move on to a more conventional computer."

CORE AREA 6 - ENVIRONMENTAL CONTROL

A Computer-Based Environmental Control System

All of the skills necessary for Oliver to operate an environmental control system, together with the equipment necessary to develop them, have been described at various

points in previous sections. The degree of integrated complexity and customised work that such a system entails if it is to meet the specific day-to-day needs of the user within the parameters of his capabilities means not only considerable financial outlay, but also dependence on one supplier. The following extract from a proposal drawn up by Mr. J. H. Taylor of Elfin Systems not only illustrates the equipment involved in a typical system but also gives an insight into the total service that needs to be offered by a supplier to a client who, like Oliver, has developing needs.

An Elfin Communicator and Environmental Control System:-

Hardware (Communicator):

Video Genie EG 3003 microcomputer system with 16K memory and integral cassette player. Braid speech synthesiser unit. Green screen computer video display unit.

Three special sets of inputs, one incorporating an electronic switch to harness the small residual movement in Oliver's fingers, one set of head switches, and a light touch thumb switch.

Environmental Controls:

A full environmental control system to give full control over electrical appliances and the family television set. Provision for enhancing the system at a later date to operate electrical toys or to program and operate a microcomputer if Oliver's development is sufficient.

A mains electricity control system operating without control wiring with control signals transmitted through the existing house wiring to receiver units plugged into the 13 amp sockets. Two receiver units with provision for a further fourteen. A television control using a remote control adaptor, giving full access to the Teletext service.

Software:

Provision of one duplicate copy of a suitable ELFIN communicator programme.

User Inputs:

Provision of three sets of user inputs as detailed above, selected to suit Oliver's requirements at the time the system is commissioned.

Required additional inputs at a charge based on the costs ruling at the time of supply.

The system as outlined presents two stark challenges to the statutory authorities. Firstly, to what extent is the Education Services willing or able to provide a comparable system in the school setting so that Oliver's education towards personal independence can begin without further delay? And secondly, to what extent are the D.H.S.S. and the Social Services willing or able to meet their responsibilities in providing a comparable system for home use which takes into account Oliver's age, abilities and potential?

Public Leaflet. 17th August 1985

THE OLIVER HOUSE PROJECT. CURA: The Co-operative Union for Rehabilitation and Advocacy

CURA is a Midlands based association of multiply-handicapped children and young people, together with their families. It aims to provide support to its members, for as long as is necessary, in their individual and distinctive quest for educational and therapeutic progress and optimal quality of life.

In particular, CURA aims to:

- disseminate information about the implications – physical, intellectual, emotional, social and spiritual – of the disabilities of members in order to promote greater care and concern among the public;
- make representations regarding individual needs to community care professionals and administrators;
- acquire and deploy staff for the care, education and therapy of member in order to ease the burden on their families;
- make available equipment and resources necessary for rehabilitation and independence.

Central to CURA's philosophy is the idea that members and their families should decide their own individual priorities and shape their own distinctive programmes for rehabilitation. The ultimate aim is to establish a life-style as independent as possible of the constraints caused by the social and economic, as well as physical, aspects of handicap. It recognises that curative education or holistic therapy is a lifelong process of meeting co-operatively the unique special needs of each severely disabled person.

THE OLIVER HOUSE PROJECT aims in the first instance to set up a therapeutic community of two or three young people in accordance with the ideals of CURA. The Project is named after Oliver Medhurst, the childhood victim of a road accident, whose urgent needs have inspired the initial planning. Its main

aim is to purchase and equip premises suitable to the needs of the severely handicapped, situated within the wider community, and providing an environment in which care may be undertaken by professionals, volunteers, and the friends and families of the disabled.

WHY?

Parents of severely multiply-handicapped children have particular difficulties in facing the future. Once the support provided by statutory education has come to an end, the handicapped young person can either be placed in an institution, or continue to be cared-for by ageing parents who must inevitably relinquish their duties as their powers fail. Long-stay hospitals must be subject to strict routine, be under constant financial pressure to accept a wide variety of patients, and be compelled frequently to ignore the distinctive needs of any particular individual or sub-group.

WHAT?

THE OLIVER HOUSE PROJECT aims to overcome these problems by providing:

- **premises** totally adapted to the needs of the severely disabled occupants, using technology to reduce the labour-intensiveness of care and to facilitate independence wherever possible;
- **facilities** for live-in or visiting care staff;
- **an environment** in which relatives, friends and volunteers are encouraged to contribute to care support;
- **a home** integrated with the wider community and accessible to public services and amenities;
- **an open, supportive community** which provides optimal opportunities for social interaction and the economical deployment of educational and therapeutic support;
- **independence** from impersonal bureaucracies in the context of an association dedicated to the special needs of the community members.

HOW?

The Project is sponsored by CURA (The Co-operative Union for Rehabilitation and Advocacy) and is financially dependent on voluntary contributions from the public.

A Board of Trustees has general oversight of CURA and THE OLIVER HOUSE PROJECT and carries legal responsibility.

A General Council is responsible for shaping and implementing the policies of CURA.

A Management Committee is responsible for the running of THE OLIVER HOUSE PROJECT.

TARGET DATE FOR OPENING: 1990

▪ END OF PART 1 ▪

PART 2: THE LONG HAUL. 1986-2012

TEN YEARS ON: SOME REFLECTIONS

In some ways the pain increases as time goes on. Those dreams which gave hope are gradually seen to be delusions rather than visions.

Our hope that Oliver would recover some functional use of his limbs has not been fulfilled. If anything, we have seen a deterioration as joints have calcified, unused muscles have wasted, and contractures have become more severe. Major spinal surgery was necessary (in 1990) to stabilise his posture. In 1987 a bout of nearly-fatal pneumonia was a shock which raised a host of forgotten demons.

No speech has returned. Some days before his accident Oliver had won a choir-scholarship at Leicester Cathedral. It is still impossible to hear a boy singing without acute emotional pain. Knowing through a simple "Yes/No" code that Oliver was intellectually intact, we placed great hopes in technology, and I became something of an expert in this rapidly developing field. But it was all in vain. While computers have provided Oliver with some worthwhile educational activities, they have not proven to be the panacea we expected. Oliver's particular pattern of visual difficulties and cerebral-processing problems means that use of the equipment is slow and frustrating.

Perhaps the greatest blow was having to "admit defeat" and send our son away to boarding school. By 1985 we were emotionally drained and exhausted and our teenage daughter was beginning to react. Our attempts to obtain adequate resources in the community became a running battle. My career, our means of livelihood and financial independence, was beginning to suffer. Our dwindling social relationships were dominated by our constant demands on a small, forbearant circle of friends whose "normal" family pre-occupations became increasingly remote from our own. Eventually, the time came for us to swallow our pride and our deep sense that we were betraying Oliver, and ask for a residential placement. Since 1985 Oliver has spent only three months of the year at home. This has given us time to adjust as far as possible and to prepare for the very demanding arrangements that will come into operation when Oliver comes home permanently in 1993.

Letter. 15 November 1989. To: The Headmaster, Penhurst School, Chipping Norton, Oxon.

Dear Mr. S.,

OLIVER WILLIAM MEDHURST. [D.o.B. 10-09-73]
1981 Education Act
Further Parental Representations

Thankyou for chairing Oliver's Review meeting at Penhurst on the 10th. Handling a meeting of such size required great skill and we were very pleased that you were able to ensure that the occasion was both productive and informative.

Having reflected on some of the contributions to the discussion we feel that we must express concern about one or two matters relating to the two items on the agenda. Given the increasing urgency of the situation we must, perforce, be very direct.

16+ PLACEMENT

We were surprised at how little specific information there appeared to be about appropriate institutions available to the meeting; such information is now a matter of urgency. We would suggest approaches to the following schools/colleges. (*list follows*)

Meanwhile, we note that representatives from Portland College will be visiting Penhurst for the purpose of assessing Oliver today. Ms. K. has promised us a copy of their report and we will study this with great interest.

MICRO-ELECTRONIC AIDS

We very much hope that Mr. M. will obtain leave from Hereford and Worcester Education Authority to follow through his preliminary assessment of the 5th January 1989. It seemed apparent at the meeting that your Mr. W. had [potentially] a great deal to say about Oliver's needs. Once again, it was a pity that more specific information was not available to the meeting. Oliver's progress [or lack of it] so far needs to be considered. You may recall that I asked for a Report specifically from Mr. W. in a letter dated 8 Oct. 1986. In your reply of 15 Oct. you assured me that he would provide one. In the event, a report did not appear. My plea to him was

re-iterated during our discussions on the 5th of January this year; once again to no effect. I am therefore once again obliged to ask

THAT Mr. W. [N.C.H. Micro-electronics Resources Adviser] be asked to provide a detailed report on Oliver's work with such equipment since 1985, but with particular reference to the current programme. This Report should indicate

Hardware currently in use;

Software currently in use;

The skills which are being developed, and how;

Oliver's current rate of progress and how this is being assessed.

We feel that it is reasonable to ask for such a report to be available before Easter 1990; it is, we feel, an essential tool in promoting Oliver's progress beyond the age of 16. In the few years that remain of Oliver's formal education we cannot afford to waste time "re-inventing the wheel".

We look forward to a fruitful outcome to the statutory re-assessment process; meanwhile, many thanks for the part you have played in what progress has been made so far.

Circular. 10 November 1989

Parental Representations. Education Act 1981.

1. PREAMBLE

In this statutory re-assessment of our son's special educational needs we wish to focus on one crucial aspect: namely, micro-electronic resources which may further Oliver's education towards any degree of independence which he may enjoy in the future. Such independence falls into two categories:

[a] COMMUNICATION. [Oliver cannot talk]

[b] CONTROL. [Oliver has little functional movement]

2. THE CURRENT SITUATION

The statutory agencies have provided two pieces of equipment:

[a] A "Light-Talker", on loan from Leics. Speech Therapy Dept. Input: single-switch operated by the head. Process: visual scanning by L.E.D. of "Minspeak" symbols. Output: synthesised speech; one-line liquid-crystal display.

[b] Two P.O.S.S.U.M. switches for head-usage mounted on a microphone-stand, provided by Leics. Health Authority.

3. IDENTIFIED NEEDS

[a] Oliver has no equipment for computer-assisted learning [C.A.L.] provided by a statutory agency.

[b] Oliver has no C.A.L. equipment for homework.

[c] Oliver has no environmental control system.

[d] In any 16+ placement Oliver will be expected to bring his own equipment to the receiving institution.

4. PROPOSAL

THAT Hereford and Worcester Education Authority provide equipment on which to base Oliver's education up to the age of 19 in the areas of C.A.L., communication, and control.

Correlations may be made between these areas and the subjects laid down in the National Curriculum.

This proposal relates to the fact that the "Light-Talker" may be interfaced with a computer-system, enabling input by Oliver to such a system. The technical parameters of the necessary system are as follows:-

[a] processor: I.B.M.-compatible 256K - 640K Portable or "luggable"

[b] data storage: Dual disc-drive MS-DOS

[c] display: Conventional V.D.U. or gas plasma

[d] output: Serial port [RS 232C] Other ports if possible

[e] interface: From LIBERATOR, suppliers of the "Light-Talker"

5. IMPLEMENTATION

Our experience over the last seven years indicates that resources are only likely to be made available and/or used if professionals involved with Oliver feel that they have direct control over the provision. The problem at the moment is that in the current situation the "buck" is likely to be passed between either the different statutory agencies, or the statutory agencies and the receiving institutions, or different possible receiving institutions, or professionals within a statutory agency, or professionals within receiving institutions, or agencies/institutions and charities, or different charities.

Meanwhile, Oliver's needs remain unmet.

As far as we are concerned, responsibilities should be allocated as follows:-

[a] Provision and servicing arrangements: Hereford and Worcester Education Authority [Mrs. C.]

[b] Technical advice and recommendations: Hereford and Worcester Education Authority [Mr. M.]

[c] Development and usage: receiving institution [member of teaching staff responsible for micro-electronic resources]

Unless we are informed otherwise, we will assume that the above are to be regarded as the accountable agents in any

correspondence with the appropriate authorities or with our representatives.

Letter. 17 November 1989. To: Ms. P. A. C., Hereford and Worcester County Psychological Service

Dear Ms. C.,

Thankyou for your letter of 9th November 1989. I remember well the content of our meeting last summer. In view of your proposed course of action at that time, and in view of this reiterated statement of your adopted role, we would be very grateful if you would take particular note of our remarks under the heading "16+ PLACEMENT" in our "Further Parental Representations" of the 15th of November. Although it is now too late for the Leaver's Review, we nevertheless await any advice which you have to offer with eager anticipation.

Letter. 11 September 1991. To: The Rt. Hon. A. M. V. C., M.P., Margaret Thatcher House, 35 Mill Street, Kidderminster, Worcs. DY11 6XB

Dear Mr. C.,

Thankyou for your letter of The 9th September 1992. Oliver's preferred solution to the complications that seem to have arisen is a fresh two-year placement. He is therefore particularly concerned about the response of the Authority to his acceptance of the offer of a place at Hereward College, Coventry - particularly in view of the fact that their term began on 2 September. After careful consideration of all the information currently at his disposal, Oliver has expressed to us a desire not to return to Nash House. He looks forward to hearing anything positive very soon. We hope that he will not be disappointed!

Leaflet. August 1992

We rejoice that our son lives. He is a joy to be with. His radiant personality and wonderful sense of humour transfigure the pain and tragedy of his situation and the bleakness of his future. We, his parents, are committed to caring for him as long as our strength endures. Even if physically hard, it is not a sad and demoralising task: we love our son, and he gives us much in return. But there are shadows which fall across our home. We have come to know our limitations. The time has come once again for us to swallow our pride and seek the help of the community.

Having shared our story, are you willing or able to help us? If the answer is "Yes", then please read on

THE OLIVER MEDHURST APPEAL. 1992-3

PLEASE consider the following:-

1. OLIVER is now 18. He returns home "for good" in 1993.
2. Mobility is the key to OLIVER's quality of life. Getting "out and about" in his wheelchair is essential for this teenager, who can do so little to entertain himself.
3. The Medhursts are obliged to be a one-income family. Their only means of transport in an unadapted Metro. OLIVER has to be lifted bodily in and out. Both parents have had to seek medical help with back pain.

17 AUGUST 1992 IS THE TENTH ANNIVERSARY OF OLIVER'S ACCIDENT. HE COMES HOME ONE YEAR LATER. CAN YOU HELP?

Our need is for a special "roll-on/roll-off" vehicle that will enable any carer to load OLIVER onto a vehicle without physical risk to themselves. Such vehicles do not come cheap. We estimate that we need at least £20,000 to purchase one. We do not have the financial means, but we are convinced that this is not a luxury if OLIVER is not to become a prisoner in his own home.

Letter. 26 April 1992. To: The Head of Care, Hereward College, Coventry

Dear Ms. Kendrick,

Oliver has asked us to write to you to point out that he has just purchased a "Discman" and is quite keen on taking it around with earphones during the day to play at appropriate times. There is a set of speakers in lieu of the earphones to use in his room at other times. Could you please bring the attached notice to the attention of colleagues or place it on display in his room? With thanks.

please . . .

1. place a disc in the player
2. attach the player to Oliver by means of the strap
3. connect the earphones
4. press the play button (far right on console)
when appropriate . . .
5. plug speakers into earphone socket
6. plug speakers into mains
7. plug disc-player into mains to save battery

Letter. 26 April 1992. Dr. R. W. Access Centre, Hereward College, Coventry

Dear Bob,

When we last saw you, we mentioned the need to give Oliver's sponsors some occasional feedback.

The lady who provided the funds for all of Oliver's Toshiba equipment is:-

Mrs. J.H. B. (*address*)

She learned of Oliver's situation by accident just over a year ago and has been extremely generous since then. Although we correspond, no-one in the family has met her in person. I guess she must be in her sixties and a widow.

A letter from Oliver of a positive kind produced on appropriate equipment would be very apposite at this time.

Letter. 1st August 1994. To: whom it may concern.

OLIVER MEDHURST - SPIRITUAL NEEDS

Oliver took up permanent residence in "Saltways" Cheshire Home, Redditch, on 1st August 1994. To those who have not a great deal of experience with the cerebral palsied, Oliver's handicaps can be daunting: he only has limited functional movement in his head, and no speech. The "shock-value" of his handicap is compounded by the fact that his condition arises from a road-traffic accident when he was eight years old. (Oliver's d.o.b. is 10.09.73; the date of the accident - 17.08.82 - is a particularly sensitive anniversary for the family.)

In view of the initial impact of his condition, it is necessary to remind interested parties of the following:-

(a) Oliver is of at least normal intelligence, although his condition means that he is sometimes unable to inhibit socially inappropriate reactions (eg. laughter during sermons or at solemn moments in liturgy).

(b) Oliver is a sincere Christian and particularly enjoys religious music and worship.

Letter. 22nd August 1996. To: Mr J. B. The Disability Team, Wendron Centre, Chapel Street, Bromsgrove, WORCS. B60 2BQ

Dear J.,

OLIVER MEDHURST - FINANCIAL MATTERS

We enclose a copy of a letter which we have sent to L. H.C.

As you will know, the ILF grant came into operation on 25 July 196. We are hoping to start paying invoices for afternoon care directly from 3rd September. It would be helpful if you could send us the following:-

(a) An invoice for afternoon care between 25 July and 26 August; we will be able to pay this immediately.

(b) An invoice for "extra" (ie. evening and night) care during the period

7-22 August; we will pay this just as soon as we have accumulated funds from savings elsewhere (eg. suspension of afternoon care 27 August to 2 September).

(c) An invoice for Oliver's own personal financial contribution to care to date.

We enclose a invoice which we have received from The Winged Fellowship. Please note that they are still holding a £50 deposit paid by us.

Letter. 25th August 1996. To: Mrs L. H.-C. Independent Care Service, "Sandalwood", 25 Comberton Road, Kidderminster, Worcs. DY10 3DL

Dear Mrs H.-C.

OPERATIVES FOR THE OLIVER MEDHURST HOME

Please accept our grateful thanks for all your good services in providing care for Oliver during our annual holiday 7-22 August.

We are now writing to inform you that as from Tuesday 27 August the funding arrangements for daily care for Oliver from noon onwards have changed. Agencies employed for afternoon and evening arrangements are invited to negotiate terms and conditions and send invoices directly to us as Oliver's agents. (Please note that Mrs Medhurst holds Enduring Power of Attorney for Oliver's financial affairs.) Morning care will continue to be contracted by Social Services with the current arrangements unchanged.

In order to smooth the transition to the new permanent arrangements and to review our requirements we are suspending afternoon care for the period Tuesday 27 August to Monday 2 September inclusive. The two carers involved - R. and M. - have been informed of our intention. We shall be "at home" throughout this period; please do not hesitate to phone or call to discuss future arrangements inside or outside office hours.

We hope that this hiatus can be viewed positively by you and your operatives as an opportunity to review the nature of the service you are able to offer to Oliver and the home in which he resides with us. As you know, Oliver wishes to go out and about in the afternoon whenever possible, and this is an important element in his quality of life. When the weather is inclement, there is a limit to the recreational activities which can be pursued with Oliver during the session, although we are always to co-operate with carers' own initiatives. We do not feel it appropriate to spend scarce resources on employing people to "sit" with Oliver when Mrs Medhurst can be present in the house.

As we have indicated to you before, Oliver is part of a household of three adults in which all resources and financial commitments are shared. There can therefore be no natural distinction between Oliver's "area" or "possessions" and our own. Furthermore, it is vital that Mrs Medhurst, as Principal Carer and Care Manager, does not come under undue stress. If she does, the current universally beneficial arrangement will collapse. This means that we must ask agency operatives to perform general and undifferentiated domestic duties as directed by Mrs Medhurst during inclement weather and at other times as deemed appropriate by us. If this is not acceptable to you, care may be suspended during seasons of inclement weather and a domestic help agency may be employed by us at these times, or alternative agencies or individuals may be employed who have the required flexibility.

If you or individual carers are unwilling to countenance more general domestic duties as operatives at our home then it is vital that you inform us as soon as possible during the next seven days so that we can make alternative arrangements. The current arrangement will automatically be terminated on 2 September. If, on the other hand, you and the current afternoon carers are willing to work as operatives within the terms and conditions indicated in this letter we all look forward to a resumption of their new duties on 3 September.

If we do not hear from you before that date we will assume the new arrangements are acceptable to the agency. A copy of this letter has been given to R. and M. and sent to J. B. to speed the consultation process. It would be helpful if invoices could be

sent to us on a strict four-week cycle commencing 16 September 1996.

Unless we receive written information to the contrary, we are assuming that the agency will be held liable for any mishap involving Oliver or his property and any operative sent by the agency, and that the agency fee contributes towards the cost of your insurance premium.

We have all been pleased with the service we have received from you within the terms of the Social Services contract; we sincerely hope that you will feel able to offer us a comparable service under the terms outlined above. We look forward to hearing from you at any time within the next seven days.

Letter. 29th September 1997. To: J. F., Service Manager Physical Disabilities, Social Services Department, Bellway House, 7 Worcester Road, Bromsgrove, Worcs. B61 7DL

Dear Mrs F.

APPLICATION FOR DIRECT PAYMENTS FOR OLIVER MEDHURST

Thankyou for your letter of 11 September 1997.

We note that the direct payments pilot project is due to commence on 1st October 1997, and that information will be available in late September. We look forward to receiving written information when it has been published and to discussing the matter further with J. B. or P. F. as you suggest.

As part of our application for direct payments for our son we enclose a statement of our own assessment of Oliver's "formal" care needs ("informal" care being provided by ourselves).

We are now asking for assistance in approaching the I.L.F. for a re-assessment of their contribution to Oliver's care as soon as possible, prior to revising and establishing the contribution to be made by the Social Services Department. We are instigating this process on the grounds that we are currently having to subsidise "formal" care from our own pocket.

In order to prevent any delay to the possible implementation of direct payments to Oliver we would be grateful for your assistance in expediting these matters.

Letter. 13th April 1999. To: The Director of Social Services, County Hall, Spetchley Road, Worcester WR5 2NP

Dear Mr G.

We are writing to you in connection with our son Oliver, who sustained extensive brain damage as a result of a road traffic accident when he was 8 years old in 1982. Oliver is very severely physically disabled, although relatively unimpaired cognitively. Since he has no functional movement and cannot speak, he needs a high level of care on a 24-hour basis coupled with a quality of life commensurate with his intelligence and full awareness of his surroundings.

Oliver had been in residential care up till November 1995 when we took the joint decision to care for him in our home in Kidderminster. Since that time day-care has been funded by Social Services, for which we are grateful. We are sorry to say, however, that one or two problems have arisen.

Some of the day-care is contracted and managed by ourselves using monies provided directly to us by The Independent Living Fund. Other care, however, is provided by commercial agencies contracted and managed by the local Social Services offices in Bromsgrove. It is with the latter that we have experienced problems.

The commercial agencies are extremely reluctant to have dealings with Oliver's advocates and representatives - ie. ourselves - except when they are unable to provide the contracted service. At such times, it is automatically assumed that we will step into the breach. We appreciate that, human nature being as it is, a commercial organisation will be primarily interested in the opinion of the paymaster (ie. Social Services). Unfortunately, the Social Workers responsible are remote from the day-to-day situation and the problems that arise, and are generally reluctant to criticise or call to account the agencies on which they depend to provide the service. Closer engagement with, and monitoring of the agencies would entail more work for the local Social Services Office - extra work which they are, not surprisingly, reluctant to

embrace with open arms. Meanwhile, while we *are* willing to monitor the quality of the service, scant regard is paid to our opinions by the agencies concerned. Indeed, there has been more than a hint from agencies that criticism from us will lead to a curtailment or even total withdrawal of the service, and this implicit threat has been actualised on two previous occasions by two different agencies. The same development appears now to be under way with a third agency, and the local Social Services Office appears reluctant to grasp the nettle of restraining this potential or actual exploitation of dependence which has very much the flavour of "disciplinary" action against a recalcitrant client.

Such frustrations are tolerable provided that an efficient service is provided by the agencies. Unfortunately, in the last three years we have experienced three major crises in which the service has been severely curtailed or has collapsed altogether. In these situations it has been obvious that the local Social Services office has been completely out of its depth, and, despite its nominal role in managing the service has been unable to deal with the problem of defaults.

The first crisis occurred in January 1997 when the agency withdrew its service at short notice as part of an attempt to increase its fees. We immediately contacted our part-time Social Worker, who indicated that he was unable to help until his return to work the following week. Naturally, we "plugged the gap" ourselves, despite our employment commitments and back injuries. In the event, we were able to hire carers ourselves by "borrowing" money from ILF funds and presenting Social Services with a bill.

At this time it became obvious to us that a far more effective service could be provided for Oliver if Social Services funds were paid directly to us, thereby enabling us to hire carers ourselves (as was already happening with ILF funds). Such an arrangement would be more flexible, more efficiently managed, and have the important effect of making agencies more responsive to criticism from those fully aware of the situation on a day-to-day basis.

In view of this conviction, we were delighted to hear that in April 1997 legislation came into force which allowed local authorities to make such arrangements for "Direct Payments".

Not surprisingly, therefore, we made a application for such payments in February 1997.

Since then, there has been little progress, and we are asking you to give a considered response to the following:-

1. It is now over two years since our application and the situation has not been resolved.
2. As result of a formal complaint about the delay we received an indication in July 1998 that we would be granted Direct Payments. Since then we have received no further details and there has been no observable progress.
3. No information has been provided to us regarding the operation of the scheme eg. administrative parameters for those receiving payments, the time-scale to be expected in dealing with applications, procedures for application, and officers responsible for dealing with applications.
4. Since the concerns outlined in (3) were not addressed in the response to our complaint - which seemed to consist primarily in a plea for sympathy for the professionals concerned in setting up the scheme - we exercised our right to ask that our complaint be referred to a Review Panel. This request has been ignored.
5. In the period since our application there have been two further periods of default in which we have had to make our own arrangements for hiring care by "borrowing" from ILF funds and sending an invoice to Worcestershire County Council.

It is impossible to communicate to paid professionals remote from our home situation the amount of stress which such a situation can impose on a family which already has its fair share of burdens. Indeed, this stress, which has had some medical repercussions, has led us to regard our application as for a time in abeyance. But recent experience with a defaulting agency has led us to return to our application with a renewed conviction that Direct Payments provides the only real solution to these recurring problems.

Nothing in our dealings with Worcestershire County Council - which have entailed the writing of over 30 letters on this

specific issue – has dispelled the suspicion that the department responsible for handling complaints is reluctant to criticise fellow professionals in the same public service. Furthermore, our previous attempts to approach you leave us in no doubt that you will pass this letter on to a junior colleague who will have the specific brief of giving a merely self-justifying response without any attempt to move matters on in a positive way. If this happens again, we will have no choice but to refer our concerns elsewhere.

Letter. 29th May 1999. To: J. B. Social Worker, Physical Disability Team, Wendron Centre, Chapel Street, Bromsgrove, Worcs. B60 2BQ

Dear Jack

APPLICATION FOR DIRECT PAYMENTS FOR OLIVER MEDHURST (22.02.97)

Thankyou for your letters of 18 and 20 May 1999.

I hope that you are able to accept the principle that an annual budget preserves our dignity more effectively than an *ad hoc* weekly dole, and that in seeking to establish this I am not "talking a load of crap" as you asserted during our meeting on the 11 May 1999.

Unfortunately, despite our lengthy discussions with you last December, during which we thought that we were moving to respite care on a six-weekly cycle, we once again seem to find ourselves in an "*ad hoc* dole" situation. Hence our concern that respite care should be built into any proposed Direct Payments package.

You may have heard that, in the face of a direct refusal to fulfil his defined duties, an agency worker was recently sent away by Jackie. We do not feel that public money should be paid to people simply for watching T.V. in our house. Despite your reiterated concern at the 11 May meeting that we should not be "making a profit" from Direct Payments, you will find that we have always been assiduous in pursuing value for taxpayers' money.

We look forward to hearing the results of "senior staff" deliberations soon regarding a viable level of financing for Oliver's needs which takes into account the savings to the Council which our input would bring and which would prevent us from being effectively penalised for trying to improve the quality of his care.

Editor's note: Phillip Medhurst suffered a heart-attack in October 2000. The Medhursts formally separated in 2002, and Oliver was placed in residential care.

Letter. 12 June 2003. To: C. M., Physical Disability Team, Worcestershire Social Services

Dear Ms M.

I refer to your letter of 6th June 2003.

It is a depressing illustration of the lengths to which you and your allies are willing to go to in order to undermine any attempt we may make to promote our son's welfare. As you are no doubt well aware, it was this chronic inability to listen which resulted in Oliver's current incarceration in an Old People's Home.

Be that as it may, during a visit by Mrs. Medhurst and myself on Sunday 8th June 2003 it became painfully obvious that Oliver was suffering extreme discomfort on his bottom. In our assessment, based on 20 years' close contact with our son, his weight loss is a contributory factor to this disturbing state of affairs. Our observation of his weight loss is corroborated by two independent witnesses who know Oliver well, and is undoubtedly (in our expert opinion) the result of Lickhill Manor not investing enough time and labour in his feeding regime.

As regards Oliver's quality of life, it is now painfully obvious that you intend to renege on your promise to incorporate Oliver into a Young People's Disabled Unit to be constructed on the Lickhill Manor site. Since, under Ms D.'s tutelage, with her aggressive and uncritical support of commercial

organisations and her consistently hostile stance towards Oliver's parents, it would be madness for us to relinquish our close supervision of our son's care, it seems to us obvious that there are now three alternatives:-

1. Improve the style and quality of Oliver's care in his current placement;
2. Provide a more appropriate placement within the same locality;
3. Provide funding for 24-hour care in a two-bedroomed bungalow which we have acquired for this purpose in B., to be managed on site by myself, with Oliver's mother in moral and emotional support while residing nearby.

The third option precludes any *physical* input to Oliver's care by myself or Mrs Medhurst – Mrs Medhurst has a damaged back and I have cardio-vascular problems. In any case, we feel it would be foolish for us to further sacrifice our health and welfare in the face of Social Services' evident parsimony with regard to the domiciliary option and equally evident open-handedness when it comes to commercial organisations. Oliver was ejected from his own home in 2001 as a result of the under-funding of Direct Payments. Give us a budget comparable to the one being given to Lickhill Manor (including the swingeing price-rises which have gone through "on the nod"), and it seems to us that, with some minor alterations to the premises in question, we are "in business" with regard to the domiciliary option.

Provided that it gives you sufficient time to (1) do your homework on the above options (2) introduce these options to your many colleagues, and (3) enable those colleagues to send us a written introduction to themselves and their terms of reference before the meeting, I can see no reason why the proposed meeting should not take place on 26 June 2003. I propose that this takes place at the following address

You will no doubt write to me very soon if you prefer the earlier date, together with a list of participants and a written account of any specific proposals which you intend to bring to the meeting. You will also wish to consult with Mrs Medhurst. This will undoubtedly help to avoid the fiasco which we had to endure when we last tried to introduce proposals for our son's welfare in 2001.

Letter. 16th July 2003. To: S. D., Physical Disability Team, Worcestershire Social Services.

Dear Ms D.

I note with the utmost regret that you have ignored my invitation to a case conference for our son Oliver at the above address on 21st July. I note also that you and S. C. Care held a case conference at L. Manor on 26th June in our absence and against our express wishes. This is a very serious situation, and Mrs Medhurst and myself will be considering our response over the next few weeks.

I understand also that you have composed a letter to me dated 11th July. I still have not received this letter, although Mrs Medhurst received a copy on 12th July. It is difficult to tell whether this is the result of crass manipulation or incompetence; in case it is only the latter I will respond to some of its points.

In the as yet unreceived letter you invite me to a meeting with yourself on 31st July. Since (I have discovered) Ms M. met with Mrs Medhurst on 10th July, and since Mrs Medhurst and myself are of one mind about what is best for our son, such a meeting would be superfluous. I suggest you continue to liaise with and inform Mrs Medhurst if there are any further developments in response to our recent proposals. Not surprisingly in view of the underfunding crisis which destroyed our last Direct Payments arrangement, Mrs Medhurst and Oliver himself have mixed feelings about him joining me at the above address; unfortunately, you have deprived us yet again of the opportunity of airing our concerns in an appropriate context.

In the same unreceived letter you propose an "independent" advocate. As you are aware, when we last acceded to such a proposal we found ourselves, to our horror, dealing with an *agent provocateur* in the pay of Worcestershire County Council whose input was entirely negative. Meanwhile, our urgent pleas for the adequate funding of our son's care went unheeded and Oliver was shunted into a (generously funded) old people's home/home for the mentally handicapped where he has remained ever since.

Our response to this unfortunate state of affairs will depend on what efforts (if any) are made to repair the damage which has been done by the department which throughout this difficult period has been under your tutelage. The style of response to our recent legitimate concerns about Oliver's weight-loss has not inspired confidence. Needless to say, as the person holding the Enduring Power of Attorney for Oliver, my approval will have to be sought and obtained for any present or future arrangement for his care.

Editor's note: The Medhursts divorced in 2004. Oliver was given the tenancy of a bungalow by a housing association (Contour Housing), and social services arranged a live-in care regime.

Letter. 28th March 2005. To: M. H., Physical Disability Team.

Dear Ms H.

I refer to my letters of 12th January and 23rd March 2005. Unfortunately, the dialogue which these letters were aimed at instigating has not taken place. Indeed, my recent attempt to establish contact with the Physical Disability Team has left a great deal to be desired. While I am happy to put money towards the *fait accompli* of Oliver's forthcoming holiday, I am not convinced that extra resources which could be made available by me would be used solely for his benefit – and not be used to relieve Social Services and those working directly with Oliver of their financial and other responsibilities.

In this respect, the experiment has revived painful memories of the Direct Payments fiasco, when the extra resources in terms of the time and energy of Oliver's parents were misused in the same way and chronic under-funding of the scheme and Social Services' refusal to heed warnings led to the collapse of the partnership, a deterioration in Oliver's quality of life, and ultimately a false economy.

As long as Social Services show a habitual tight-fistedness towards private benefactors (such as Oliver's family), a loose open-handedness towards commercial organisations (such as care agencies and transport companies), and a certain dilatoriness in the management of Oliver's care it seems we will not have a basis for co-operation.

In order to conclude the current experiment I have left some cash with Oliver's sister on the understanding that she has complete discretion as to how she spends it – if necessary in consultation with Oliver's mother. Once this money has run out I shall be keeping my own counsel as to how I spend money on Oliver in future. Since I have never been invited to take part in any of Oliver's Reviews, this is in fact a return to the *status quo*. Please deal directly with Oliver's sister and mother with regard to any outstanding business.

Letter. 26th June 2006. To: C. E., Helping Hands Care Agency

Dear Ms E.

Thankyou for allowing me to see you last Friday 23rd June in order to express some concerns about aspects of my son Oliver's care. Thankyou also for your commitment to making appropriate changes in personnel from today.

I hope that as a result of our shared concern Oliver's feeding regime will be reviewed and renewed. This is because Oliver's optimal weight needs to be maintained in order to prevent the rapid loss which can come about because of calories being constantly burned by contractures and spasms. If Oliver loses weight then there is no doubt in my mind (from more than two decades of observation) that he will experience skin problems, not the least of these being pressure sores. Oliver enjoys his food: it is an important component of his quality of life. Because of his limited range of mastication, feeding him may prove to be tedious, but well worth the effort. It is important that the texture of food is not broken down (ie. mashed); the corollary of this is that the food should be well sauced and lubricated with drinks. If bulk is increased, as it needs to be, then Oliver is likely to suffer from constipation. Fresh fruit and vegetables are therefore an important part of his diet.

I hope also that increased attention will be paid to Oliver's personal hygiene. There is absolutely no reason why he should smell of stale urine, or that his continence aid should be exposed, or that his oral hygiene should be neglected, or that he should be unshaven or otherwise unkempt. This is a dignity issue, and important for Oliver's self-esteem whether he has visitors or not.

I appreciate that Oliver's seating arrangements are problematical. Having purchased an adjustable armchair and a vibrating cushion I am naturally disappointed that these have never (to my knowledge) been used. Perhaps now is the time to consider installing a hoist rail in Oliver's sitting room so that he can be transferred between a range of seating arrangements. It is simply not acceptable to assume that pressure-sores are inevitable; the present situation cannot be allowed to continue. The pain caused by these sores is making Oliver's life miserable. On the other hand, leaving Oliver for long periods on his bed is a massive inroad into his quality of life.

The latter issue raises the question of the role of Oliver's supplementary care in assisting with his transfer by hoist. It is too easy to assert that "Oliver wants to sleep" thus leaving personnel free to pursue other agendas – including, as happened on Thursday 22nd June, leaving Oliver alone in the house. Also, I feel that that visiting carers should be counselled against any attempt to rush their assistance in order to free up time for themselves. For example, when I was spending New Year's Eve with my son a carer marched in at 8.30 p.m. and demanded that Oliver be put to bed immediately – no doubt so that she could get home early for her own enjoyment of the festivities. If staff are being paid by time rather than by task, this is completely unacceptable.

Above all, it is imperative that, in order to facilitate Oliver's communication, carers maintain a constant interrogatory dialogue with him concerning his situation throughout the day. I personally would not wish to undergo once more the anguish of seeing my son squirm in pain while an otherwise uncommunicative carer spends time talking to a friend on her mobile phone, or smell my son's stale urine while a carer reclines with her feet up watching T.V., or watch a carer cook a substantial meal for her own personal consumption while my son is complaining of hunger. All of these grotesque situations can be avoided by Oliver's carer asking him about his needs on a frequent basis and allowing him to use his "Yes/No" code with ease and effectiveness.

"Hope springs eternal . . . " I hope that on my next visit to Oliver in the near future all of these issues will be seen to be addressed, or begun to be addressed, so that any unpleasant repercussions can be avoided.



E-mail to H. H. care agency. 28 October 2009

Further to my 'phone call at noon today, which unfortunately you have been unable to return, I am advising you that it is very much in the Agency's interest to contact me at your earliest convenience so that you can participate in some important discussions that are currently taking place and which impact significantly on the service you provide to Oliver.

You can return my call on - or -.

E-mail to H. H. care agency. 29 October 2009

Dear C.

Thankyou for speaking to me on the phone this morning. Please forgive the rather formal tone of the rest of this letter; I am trying to leave no stone unturned! Just to recapitulate:-

Oliver's family have agreed that I should stay in residence at Oliver's home for a period in the very near future. The stay would be for no less than one week and no more than one month. This extended visit would take place at some time during the 3 months from the beginning of November 2009 to the beginning of February 2010. The aim of the stay is

exclusively to provide Oliver with emotional support at his home or elsewhere.

I would take up residence in Oliver's second bedroom. I might be accompanied for whole or part of the time by a pet animal. I would not contribute to Oliver's care, although I would be able to provide night-time cover with appropriate hands-on care between Oliver going to bed at night and Oliver getting up in the morning. I am unable to commit myself to a similar arrangement if and when Oliver goes to bed in the afternoon. I am also unable to commit myself to being Oliver's sole companion during any of his leisure-time activities, although ad hoc arrangements may be considered which do not alter in any way Oliver contracted care.

I would not expect to receive any services from Oliver's carers, such as cooking and cleaning. I would undertake all chores relating to Oliver's second bedroom (which I would wish to treat as a private area during the duration of my visit) and would aim to minimise the impact of my stay on domestic duties by endeavouring to clean up after myself after eg. using the kitchen or bathroom, or to undertake any extra chores occasioned by the presence of a pet. I would maintain a separate food supply for myself, and would not expect to impinge upon Oliver's daily living costs. I will be pleased to receive any comments or suggestions on aspects of my stay from a manager at the Agency; I would not wish to negotiate with individual carers, who should relay any concerns to their manager.

I am unable to deal with funding implications; please refer any queries about this to G. M., Disability Team Manager at the Wendron Centre in Bromsgrove. I would not expect personally to put money in or take money out with regard to Oliver's care.

If you have any comments or suggestions relating to any of the suggestions outlined above, together with any proposal regarding the dates or duration of my stay, please give these to me by letter, phone or e-mail at your earliest convenience and I will do my best to take all views into consideration if received before the final decision is made. Please note, however, that I must reserve the right to make a decision which may not coincide with the Agency's declared preferences.

I hope that these notes are useful to you. Please contact me either by post at my daughter's address above, or on my mobile phone (07766 272118), or by e-mail on phillip.medhurst@googlemail.com. Please note that I am no longer available on 01204 419098.

I have received a seasonal 'flu vaccination; I am trying to get a swine flu vaccination. May I respectfully suggest that arrangements are made for everyone having contact with Oliver to do the same?

E-mail to H. H. care agency. 4 November 2009

Dear C.

Further to my e-mail of last Thursday please note that I shall be meeting with Oliver, Oliver's mother (Jackie P.) and Oliver's step-father (Nick P.) on Sunday 8th November 2009 with a view to setting the dates and duration of my stay with Oliver. Please let me know by 'phone or e-mail before Saturday 7th November 2009 if you wish to suggest dates etc. which are convenient to the Agency.

E-mail to social worker. 6 November 2009

Dear G. M.

I am forwarding a message I have received from H. H. (*care agency*). I will discuss the options at the family meeting on Sunday. When I spoke to Ms T. the other week - a rather hurried conversation on her part - her main preoccupation seemed to be with providing accommodation for her staff, and she seemed to see it as an opportunity to bid for extra funding. I wonder what the exact financial/accommodation package is for carers? Is Oliver providing free accommodation etc.?- I will enquire further, but it is not my intention to get any extra funding for anything. We seem to be trying to make decisions for Oliver's welfare in the dark

E-mail to H. H. care agency. 6 November 2009

Dear C.

O.K. - I have spoken to S. G. at Helping Hands at 16.30 today Friday 06.11.09 and that should give me enough useful information to take to my meeting with Oliver, Oliver's mother and Oliver's stepfather this Sunday. Thankyou for your various contributions. I hope that we may find some practical ways of supporting Oliver and his mother after what has been a difficult time, particularly in the wake of the sudden and unexpected cuts by Social Services

Letter to Oliver's G.P. 18 November 2009

I was able to visit my son Oliver last weekend. I found him weak, tired, in pain and unhappy. In view of his accumulating problems I would like to moot the possibility that some kind of permanent drug-therapy be prescribed which will palliate his increasing physical discomfort and lift his mood. I have no medical expertise, but the drugs that spring to my mind are an opiate and an anti-anxiety drug such as diazepam. I appreciate that these drugs are addictive, but I personally do not see this as an issue so long as they are prescribed as a permanent measure.

Oliver himself, of course, may have different ideas, particularly in the light of his religious scruples. Could a doctor please consider this proposal and consult with Oliver? I appreciate that there are circumstances in which pain and anguish may provide a patient with the feedback necessary for recovery, but I don't think that in Oliver's case his continued suffering serves any useful purpose.

E-mail to social worker. 19 November 2009

Dear G. M.

I rang the Social Work Dept at the Alexandra Hospital today to enquire about Oliver during his latest stay and they did not appear to know that he was in hospital. I would feel much happier if a social worker were keeping an eye on things (the latest horror stories about the fate of some Alzheimers patients while in hospital - who "should" have been receiving care - have made me very nervous).

E-mail to social worker. 24 November 2009

Re: OLIVER MEDHURST in hospital again and at risk

Dear Mrs M.

I wonder where Oliver is now? And whether his pressure-sore is getting any worse (ie. the thing that killed Christopher Reeve?) No reply from his home phone, and the hospital social worker dept. won't give his father any information. Congratulations on the skill of your recent deflections! Hurrah for data protection! As for the latter, see the attachment

Disgustingly yours

E-mail to Worcestershire Hospitals. 25 November 2009

Re: OLIVER MEDHURST in hospital again and at risk

Dear Ms C.

I gather from Oliver's mother and sister that there are some very unsatisfactory aspects to Oliver's care in hospital over the last six weeks, and that the staff of the various wards have not been receptive to comment. This has caused a great deal of distress to Oliver and to ourselves. I hope to forward you a full report just as soon as this is compiled - unless, of course, we can rely on the professionals to log concerns. Can we? In the meantime I would be grateful if you could send me (via e-mail) details of the hospital's complaints procedure.

E-mail to Director of Nursing, Worcester Acute Hospitals. 28 November 2009

COMPLAINT RE. OLIVER MEDHURST AT THE
ALEXANDRA HOSPITAL REDDITCH

This e-mail constitutes my formal complaint about the care of my son OLIVER MEDHURST at the ALEXANDRA HOSPITAL, REDDITCH during the period 14th November 2009 to 28th November 2009. The grounds for the complaint may be inferred from an e-mail to me from my daughter (Oliver's sister) which is being forwarded to you at the same time as this e-mail.

COMPLAINT

Text of complaint submitted 27.11.09 via Worcestershire County Council website complaints form:-

Re: my son Oliver Medhurst. Ref. A. C. at Social Services, Worcs. County Hall.

COMPLAINT 1

Between 14.10.09 and 27.11.09 Oliver was given no care support by Worcs. while in hospital. The hospital was unable to cope with care requirements. Medical complications set-in as a result of this. Worcs. staff have largely ignored the issue of Oliver's extreme vulnerability while in hospital. The following staff have been fully briefed by the family: L. H., A. C., K. O., M. M., G. M., A. S., H. C. I suggest that Social Services establish criteria for "at risk" clients (eg Alzheimer's), and either 1. supplement hospital care or 2. place such patients in a private hospital that can cope. Funding can be found by a redundancy at County Hall; eg one post of Social Services Funding Officer could be eliminated.

COMPLAINT 2

When an attempt was made to discuss these issues with Andrea Cooke on 16.10.09 she was rude and unsympathetic and failed to outline any possible course of action to palliate Oliver's suffering or the family's distress. The matter was subsequently referred to Lin Henry; no action as a result of this latter conversation has been indicated to me despite Lin Henry having been sent copy of all e-mails during the above period.

E-mail to Director of Patient Services. 21 December 2009

Dear Ms S.

I have just spoken to R. H. who has joint Power of Attorney for Oliver with her mother. She in turn has spoken today to her mother Jackie Pitt, who is Oliver's next-of-kin. Neither has any knowledge of discontinuing the Complaint for which I have sent you the evidence.

For Oliver's and everyone's sake, we have to ensure that this does not happen again. I am therefore asking you to make an adequate response to the information you have received without any further prevarication.

E-mail to Leader of Worcestershire County Council. 10 January 2010

RE. OLIVER MEDHURST OF REDDITCH

Dear Dr. L.

Since Oliver's councillors have been totally silent so far I am forwarding this message to you.

Phillip Medhurst

----- Forwarded message -----

To: A. S. (CS, Policy and Review Officer)"

Dear Ms S.

I refer to my complaint of 27th November 2009 in connection with my son Oliver Medhurst. In view of the fact that 5 (sic) social services managers are aware of Oliver's situation I feel that ample time (6 weeks so far) has elapsed for someone, somewhere, to make the necessary response.

I note also that my e-mail request of 5th December 2009 for a .pdf file in response to my complaint has not been acknowledged. This would have been extremely useful for the relevant parties at Oliver's review meeting on 13th January 2010.

To recapitulate: Oliver was denied social services funding for necessary care support while in hospital, resulting in real physical pain for a prolonged period. (The funding officer who made this decision is now enjoying paid maternity leave.) Meanwhile, a top-heavy and generously-remunerated management team appears unable to respond to repeated complaints about the refusal to meet Oliver's needs apart from the re-iterated claim that no money is available for this purpose.

**E-mail to Social Services Administrator Worcestershire.
12 January 2010**

Dear H. L.

In order to facilitate some joined-up thinking between the NHS and Social Services I am circulating the attached extract from a recent item about care of Alzheimer's patients in hospital. I believe that this patient-group offers the closest parallel to Oliver's condition and that, in view of recent publicity, there is now no longer any excuse for the current continued neglect of his special needs while in hospital, or for Social Services remaining in denial of his situation.

E-mail to Policy and Review Officer Worcestershire County Council. 19 January 2010

Fwd: MY COMPLAINT RE. OLIVER MEDHURST

Dear Ms S.

I would be grateful if you would now respond to the attached e-mail, which you appear to have ignored.

Phillip Medhurst

----- Forwarded message -----

From: Phillip Medhurst
Date: 2010/1/11
MY COMPLAINT RE. OLIVER MEDHURST
To: A. S. (Policy and Review Officer)"

Dear Ms S

Recent contact with Social Services seems to indicate that they are unaware they are under investigation. I would be grateful, therefore, if you would advise me of the status of the formal complaint which I initiated 6 weeks ago.

E-mail to Policy and Review Officer Worcestershire County Council. 27 January 2010

Re: MY COMPLAINT RE. OLIVER MEDHURST

Dear Ms S.

Further to my e-mail reply I would be grateful if you would send me (by e-mail) your address for postal correspondence so that, if necessary, I can provide you with further elucidation of my complaint to assist you towards an adequate response, and respond to the misinformation provided by L. H. (who was unaware of my conversation with A. C. until I spoke to her).

E-mail to Policy and Review Officer Worcestershire County Council. 23 March 2010

A copy of our e-mail correspondence will be forwarded to the Care Quality Commission in due course.

E-mail to Director of Nursing and Midwifery Worcestershire Hospitals. 23 March 2010

Dear H. B.

A copy of our e-mail correspondence will be forwarded to the Care Quality Commission in due course.

E-mail to Director of Patient Services Worcestershire Hospitals. 23 March 2010

Dear P. S.

Please note that a copy of our e-mail correspondence will be forwarded to the Care Quality Commission in due course.

E-mail to G.P. 26 March 2010

I am sending you a copy of a letter I have received about Oliver Medhurst from the Chief Executive of Alexandra Hospital.

I feel that it is important for Oliver's G.P. to see this letter so that, if possible, we can head off any possible complications next time he gets a chest infection

E-mail to Policy and Review Officer Worcestershire County Council. 26 March 2010

OLIVER MEDHURST OF REDDITCH. COMPLAINT TO CARE QUALITY COMMISSION

Dear Ms S.

In case anyone within your organisation is interested, I am sending you a copy of a letter I have received about Oliver Medhurst from the Chief Executive of Alexandra Hospital.

Since you have refused to make an adequate response to my recent formal complaint about the shortfall in care provided by Worcs. Social Services which resulted in considerable pain and suffering to Oliver and loss and anguish to his parents, please note that I am making a formal complaint to the Care Quality Commission.

E-mail to Policy and Review Officer Worcestershire County Council. 26 March 2010

OLIVER MEDHURST OF REDDITCH. COMPLAINT TO CARE QUALITY COMMISSION

Dear Ms S.

. . . . the complaint against Worcs. C. C. about the withholding of necessary care support by Angela Cooke and Lin Henry while Oliver was in hospital, which you have so far ignored, is still unresolved, and it is this latter (and the related pain and suffering to Oliver, and the anguish and loss of income to his parents) which has been referred to the Care Quality Commission. I hope that the documents will give managers and administrators some idea of the physical consequences of their actions.

E-mail to Policy and Review Officer Worcestershire County Council. 31 March 2010

Re: OLIVER MEDHURST OF REDDITCH. COMPLAINT TO CARE QUALITY COMMISSION

Dear Ms S.

Thankyou for your non-response. In all the annals of those who have passed by on the other side, seldom have so many been paid so much and taken so long to do so little

Letter to H. H. care agency. 16 October 2011

Dear Z. M.

I am writing to you in this first instance in your capacity as manager of Oliver's hourly care. I understand that this amounts to 31.5 hours per week. At the time of writing 14 hours of this type of care is provided in the afternoons as follows:- Tuesdays 10-30 to 14.00 (3.5 hours); Wednesdays 12.00 to 15.30 (3.5 hours); Fridays 13.00 to 16.30 (3.5 hours); and Saturdays 13.00 to 16.30 (3.5 hours). I understand that the pattern of care is sometimes altered without notice to Oliver and his live-in carer. The service user plan for this afternoon care indicates: "Carers to take Oliver out in wheelchair." During the last few months I have been able from time to time, while staying at my Kidderminster base, to observe carers during these sessions, both at close quarters in Oliver's home, and from a distance while he has been out and about. These observations were shared and notes were compared at a face-to-face meeting between myself and Oliver's mother and stepfather last week. We were able then to agree among ourselves as to what we consider to be the salient issues at this time.

You may or may not be aware of these issues. If the latter is the case, I would urge you to review the nature and quality of your provision, particularly during these afternoon sessions. In the meantime, we may proceed to further very specific observations and embody our notes in a formal written report. If this further step is found to be necessary, we would wish to ensure that our effort is not wasted, and would therefore share the content not only with the Board of "Helping Hands", but also with the agencies responsible for commissioning the care and assuring its quality. We hope that you would find this information useful in your supervision of what is (or is not) happening with Oliver in the afternoons. But whatever happens, please be assured of our continuing pro-active engagement with our son's quality of life.

E-mail to H. H. care agency. 11 November 2012

Dear Mr L.

Best to talk directly to Oliver's mother about the issues for now. I am more likely to deal with matters by means of a specific formal complaint.

Please note that Oliver's live-in carer M. K. was not involved in any way in our observations.

E-mail to professionals in Worcestershire Social Services and Worcs. Hospitals. 5 November 2012

Dear recipient

I am attaching the full record of correspondence relating to Oliver Medhurst's stay in the Alexandra Hospital (Redditch) in November 2009. This had been done by me, Oliver's father, in the hope and expectation that the mistakes made then will not be repeated.

When it became clear that Oliver needed to go into hospital I rang Oliver's social workers and Social Services administrators (Andrea Cooke and Lin Henry), begging them to fund carers to supplement Oliver's feeding regime while in hospital, and I related to them our past experiences of Oliver's hospital stays. I made it crystal-clear that his family's experience showed that medical complications would arise if this supplementary care were not provided. In the event, the necessary care was refused and Oliver was subjected to a horrific series of medical interventions aimed at circumventing the need for labour-intensive and time-consuming care. I am now making absolutely clear the likely consequences to Oliver if such a stance is repeated.

In case you were on leave of one kind or another in the spring of 2011 and missed the revelations about standards of care at the Alexandra Hospital, I am attaching some links so that ignorance is no excuse for inflicting the suffering which my son endured and the anguish caused to his family in the winter of 2009. I hope that professional integrity if not simple human decency will prompt you to listen to what Oliver's family has said and is saying before another crisis occurs.

E-mail to Oliver's sister. 18 January 2012

Photos of Oliver's latest paintings attached.

E-mail to Oliver's sister. 24 January 2012

The paintings were done with Oliver's hourly carer: H. K.

E-mail to Oliver's sister. 26 January 2012

I believe your mother fell out with H. K. the other day over the latter's unwillingness to push the wheelchair - so tread carefully - but she (I believe) is still "on" with Oliver for College on Wednesdays.